FEBRUARY 2003 VOLUME 5 NUMBER 5

MYELOMA TODAY

A PUBLICATION OF THE INTERNATIONAL MYELOMA FOUNDATION

Dear Reader,

Since 1995 the IMF has been funding research projects. We began by giving out one Junior Grant, which was awarded to Dr. Atsushi Ogata who was working on IL6 signal transduction. We were thrilled that the IMF was launching its research grant program, and to mark this important milestone we held a gala benefit and honored IMF Board member and myeloma patient, Dr. Francesca Thompson, author of the book Going for the Cure. It was a momentous occasion and the beginning of a new chapter for both the IMF and myeloma patients.

Over the years our research grant program expanded, and while we continued to fund Junior Grants, we also began to fund Senior Grants as well. The IMF's research goals are clear, to bring new people into the field of myeloma, to fund projects that will have the most immediate potential benefit for myeloma patients and to maintain the highest standards in our research grant selection process. The IMF's research grant program is made possible through the generosity of our members, people like you who believe in what we're doing and share our values and philosophy.

Just as the treatment and management of myeloma has evolved, so has the IMF's research program. In May, 2002, the IMF conducted its first ever telethon, and many of you responded generously when we called to ask if you would be willing to support a new research initiative that the IMF was launching. In just two days we raised $156,000!

I am proud to be able to report back to you that the IMF has launched not one but two very exciting new research initiatives, Bank On A Cure™ (BOAC) and the International Prognostic Index (IPI). Spearheading BOAC are two of the world's leading molecular biologists, co-chairs Dr. Gareth Morgan (University

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This issue of *Myeloma Today* is supported by Celgene Corporation

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REPORT FROM THE LOS ANGELES IMF PATIENT & FAMILY INTERACTIVE SEMINAR

Los Angeles IMF Patient & Family Interactive Seminar faculty:
Dr. Jeffrey Wolf, Dr. Robert Vescio, Dr. Morie Gertz, Dr. Jean-Luc Harousseau, Dr. Brian Durie, and Anne Grainger

By The Unknown Patient

After attending dozens of IMF Patient & Family Seminars all over the world, what Unknown reason keeps the Unknown Patient coming back? Each seminar offers something new. Something new from the faculty. Something new from the hundreds of people who come together to learn and to share. The latest IMF seminar, held in Los Angeles on January 24 and 25, 2003, was no exception.

The seminar began on Friday afternoon with a session given by Regina Swift, RN (Clinical Research Coordinator, Multiple Myeloma & Bone Metastasis Program, Cedars-Sinai Medical Center, Los Angeles, CA). She presented on "Pain Management & Quality of Life Issues." This was followed by a very useful talk by Barbara Schwerin, Esq. (Director, Cancer Legal Resource Center, Loyola Law School, Los Angeles, CA) who covered "Managing Insurance Issues."

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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.

Los Angeles Seminar – continued

IMF Director Mike Katz with presenter Barbara Schwerin, Esq.

Following these sessions, there was a great opportunity to meet new folks as well as old friends at the welcome dinner, which was preceded by a cocktail hour. The Unknown Patient was delighted to find Sheila Field and her family. Sheila is a faithful friend of the IMF and a prime mover in the Los Angeles support group. Sheila has been through a very tough year and it was wonderful to see her on the mend and

The Field Family

charming the crowd, as usual.

Sitting down to dinner, the Unknown Patient met a lovely newlywed couple, married just last month and both in their seventies. The bride was the patient. For some Unknown reason, her doctors seem to have given up on her — despite the fact that she had received only minimal treatment, she was put on morphine and told there was nothing else to be done for her. The

Mike and Regina Conti with Susie Novis

Unknown Patient and his tablemates were stunned and spent most of dinner making sure that the couple would seek another opinion ASAP.

After dinner, IMF President Susie Novis presented donor recognition awards to a number of generous IMFers. Last year, about 8,000 donors stepped up to support the IMF mission with gifts of all shapes and sizes. While the IMF does receive support from pharmaceutical companies, the bulk of its support comes from individuals whose lives have been touched by myeloma. The Unknown

Dr. Brian Durie, Susie Novis, and Regina Swift, RN

Patient is grateful to all who help make it possible for the IMF to do its good work!

On Saturday morning, the Unknown Patient got an early start, skipping the breakfast buffet to catch up with old friend Mike Katz, who was working feverishly to get the equipment ready for the Interactive program — the IMF's new system that allows attendees to get more directly involved at IMF seminars. Participants use electronic

Thelma and Abe Alkana

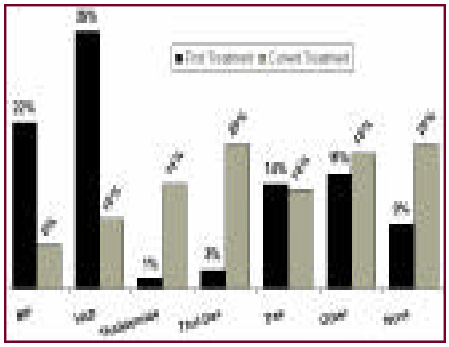
keypads to answer questions posed by the faculty. Their answers are tabulated by computer and displayed on a projection screen in front of the room. After some Unknown video problems were resolved, the system was ready to go. Mike and his Unknown friend breathed a deep sigh of relief.

The sessions started with a talk by Dr. Morie Gertz (Mayo Clinic, Rochester, MN) who explained the basics of myeloma, clearing up many Unknowns for the group. He did a wonderful job, using

Beverly and Jon Cross

real world analogies and drawing diagrams to explain what myeloma is and how it is treated.

Mike Katz then took the group through some introductory Interactive questions, revealing that 2/3 were attending their first seminar and just over 1/2 the group were patients. Over half of the patients in the group had been diagnosed over 2 years ago, with 15% reporting they were diagnosed over 5 years ago.



Next, Dr. Brian Durie (Cedars-Sinai Comprehensive Cancer Center, Los Angeles, CA) reviewed standard treatment options, which have changed quite a bit in recent years. The change was evident when participants were asked about their own first treatment and current treatment and the Interactive tool registered their responses, summarized in the graph above. The growing prominence of Thalidomide and Thaldex and the declining numbers for MP (melphalan-prednisone) and VAD (vincristine, adriamycin and doxorubicin) were striking.

Jerry and Françoise Pransky

Prof. Jean-Luc Harousseau (Founder, Intergroupe Francais du Myelome, Nantes, France) was up next to talk about Stem Cell Transplantation. Dr. Harousseau is one of the world's top experts on myeloma transplants. In fact, his study on tandem (double) transplants was chose for presentation at the plenary session of the 2002 meeting of the American Society of Hematology (ASH). Dr. Harousseau reviewed current data on autologous and allogeneic transplants. His data shows that a second autologous transplant improves survival when there is a less than complete response to the first. He also reviewed progress in allogeneic (donor) transplants, where the mini-allo is now the focus of new clinical trials. In a mini-allo, an autologous transplant is followed by a non-ablative, donor transplant (where the patient's marrow is only partially destroyed by high dose chemotherapy before the donor cells are infused).

IMF supporter and frequent volunteer Wilma Sallman with Susie Novis

Donald and Mary Spicer

Dr. Robert Vescio (Assoc. Director, Multiple Myeloma & Bone Metastasis Research Program, Cedars-Sinai Comprehensive Cancer Center, Los Angeles, CA) reviewed current approaches to managing bone disease, focusing on bisphosphonate therapies (i.e., Zometa and Aredia). Dr. Jeffrey Wolf (Director, Bone Marrow Transplantation, Alta Bates Comprehensive Cancer Center, Berkeley, CA) discussed novel therapies currently in clinical trials, including VELCADE (a.k.a. PS-341), a proteosome inhibitor, and

Please see next page

LETTERS

LOS ANGELES P&F INTERACTIVE SEMINAR

Excellent. What a terrific seminar. This was my second and, though my memory can't recall every detail of the 2002 seminar, this entire day was packed with informative material delivered in a factual yet often fun style. It was understandable to those of us who aren't savvy to real 'doctor speak.'

The new video-type slide presentations were easy to read. The Concensor buttons made me feel I was a greater participant in the seminar. It was important to me to see how others shared their personal MM experiences as well as their responses to questions 'quizzing' us on the previous presentation.

Congratulations to all of you who worked so hard to make this a tremendous learning day. The buffet lunch was also terrific and I met some great people at the luncheon table.

DICK FRIEND, *California*

MYELOMA TODAY

Thank you for another inspiring issue of Myeloma Today. Though I don't understand the medical terminology, it is so reassuring to read about new research developments and read yet another 'survivor' story and see Susie looking 'young and vibrant' as she has for the 11 years since I first met her. We sat in her living room with one volunteer and a dachshund and she told me about myeloma, just 6 months after my new husband had been diagnosed. We cried and she gave me hope and courage and I have been gaining information and hope and referrals all over the world as we have continued my husband's career and treatment. And, as we have travelled, I have continued my career as private therapist to other 'expats' and an American international charity worker in Ireland, Turkey, Holland and now, the UK. IMF is also international and has been with me in every country. You have given me support and inspiration whereever I am. So, I am including you in my book on international volunteers — 'Training Volunteers For the New Millennium: An International Connection.' It will be printed this spring. I have been consulting to UK charity organizations to share our knowledge and unique approach to volunteering and fundraising. Each issue of MT is full of great ideas… Thanks for being there.

BARBARA KAVANAGH, *England*

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LOS ANGELES SEMINAR – continued

Ray and Roberta Klein flank Susie Novis

Revimid, a thalidomide analog. The Unknown Patient couldn't help but be excited about these new treatments. There seems to be more and more progress generating new options for myeloma patients. While the ultimate benefit of these new treatments will remain Unknown until clinical trials can be completed, the pace of progress is accelerating and it can only mean good things for those of us battling this difficult disease.

Ann Grainger of the UK-based

Lucas and Johanna Dekker

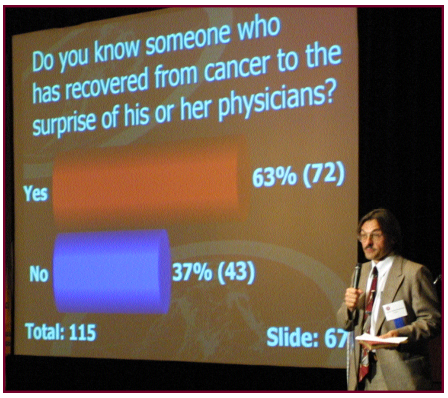
company, The Binding Site, explained their new blood test, FreeLite, which has been a boon for many, the Unknown Patient included. Some myeloma patients are "non-secretory," which means that their myeloma cells don't manufacture fully-formed immunoglobulins. Standard blood protein electrophoresis tests, which measure IgG and IgA levels in the blood, are useless for these patients, so their disease can be difficult to track. The test is also being considered as a

Herman and Ester Adler with Susie Novis

potential replacement for the 24-hour urine test, which the Unknown Patient and many others would gladly avoid if they could.

The last speaker was Dr. Lewis Mehl-Madrona, author of "Coyote Medicine," who discussed alternative healing, mind-body interaction, and spirituality, and their role in battling cancer. His talk was inspiring and invigorating, and was the perfect high-energy finale before everyone went off to the breakout sessions.

The afternoon breakout sessions provided an opportunity to get up close and



Dr. Mehl-Madrona uses the IMF's new Interactive tool to make a point that gets everyone's attention

personal with the expert faculty, as well as to network with fellow patients and caregivers. By the time the group reassembled for the wrap-up, the Unknown Patient had met many new friends and learned some exciting new things to help in his battle against myeloma. The Unknown Patient thanks the dedicated faculty for volunteering their

Fred and Virginia Gloor

time and Susie Novis and the dedicated IMF staff for making it all possible.

Don't miss the next
IMF PATIENT & FAMILY INTERACTIVE SEMINAR
March 21-22, 2003
Little Rock, AR

YOUR GIFTS AT WORK: 2003 BRIAN D. NOVIS RESEARCH GRANTS

Senior Grant recipient Dr. Federico Caligaris-Cappio (center) with lab colleagues

For 2003, the IMF is supporting a broad range of research projects. In this issue of Myeloma Today, we continue to provide summaries of funded projects, highlighting the work of Senior Grant recipient Dr. Federico Caligaris-Cappio and Junior Grant recipient Dr. Sun J. Choi.

DR. FEDERICO CALIGARIS-CAPPIO

Genetic Manipulation of Myeloma Cells to Generate Anti-Myeloma Effector T Cells

Universita Vita Salute San Raffaele
Ospedale San Raffaele
Milan, Italy

Our new approach is designed to obtain cytotoxic T lymphocytes (CTL). The purpose of this project is to develop a new approach to immunotherapy for multiple myeloma. There have been many attempts over the past 30 years to develop effective immunotherapy for patients with myeloma. This has proved to be frustratingly difficult mostly because it is both hard to trigger an active immune response against the myeloma and to sustain this response so that it can be clinically meaningful.

The development of immunotherapy approaches designed to obtain cytotoxic T lymphocytes (CTL) might help to eradicate residual tumor cells in multiple myeloma (MM) patients. The aim of our research is to obtain anti-tumor CTL using genetically engineered MM cells as antigen presenting cells. We plan to introduce genes of immunostimulatory molecules (CD80, CD40L) into MM cells through genetic manipulation with lentiviral vectors. The generation of CTL lines and clones will enable us to identify new MM antigens and ultimately to develop effective tumor vaccines with newly defined MM antigens or with MM cells engineered with immunostimulatory molecules.

As in the past, it will take time to develop the vaccine and to evaluate if an effective immune response against the myeloma can be achieved.

DR. SUN J. CHOI

Effects of Abnormal Expression of AML-1 Transcription Upon MIP-1α Production

University of Pittsburgh School of Medicine
Pittsburgh, PA

Dr. Sun J. Choi

Bone destruction is the major source of complications in multiple myeloma (MM). Factors produced by MM cells that mediate the bone destructive process are still a topic of intensive investigation. Interactions between bone cells, the bone microenvironment, and MM cells appear to play a critical role in enhancing the growth of myeloma cells and their resistance to chemotherapy. We have recently used an expression cloning approach to identify osteoclast (OCL) activating factors produced by freshly isolated MM cells from patients who have extensive bone disease. We have identified macrophage inflammatory protein-1α (MIP-1α) as a chemokine that induces human OCL formation.

It is our hypothesis that an abnormal pattern of transcription factor expression results in increased MIP-1α levels in MM patients and that this abnormal pattern of transcription factor expression also induces expression of other genes that adversely affect the prognosis of MM patients.

The goals of this proposal are to confirm that abnormal expression of the AML-1 class of transcription factors regulates MIP-1α production and bone destruction in an in vivo model of human MM bone disease and to assess the potential of IL-3 and IL-7 that are regulated by AML-1 class of TFs on the growth of MM cells and their capacity to induce OCL formation.

Editor's Note: The next issue of *Myeloma Today* will feature two new IMF initiatives — Bank on a Cure™ and the International Prognostic Index.

SALAMANCA SPOTLIGHT: IXth International Myeloma Workshop

The IXth International Myeloma Workshop will be held in Salamanca, Spain, May 23 - 27, 2003. The IMF is proud to be one of the sponsors of this important event, which is being Chaired by IMF Scientific Advisor Jesús F. San Miguel and Co-chaired by IMF Scientific Advisor Joan Bladé. In addition, the IMF will be sponsoring several workshops and roundtable discussions during this exciting conference:

May 22, 2003
International Myeloma Working Group
A committee of myeloma experts, including many IMF Scientific Advisors, their colleagues, and delegates.
Topics: IPI, BOAC, Epidemiology, Clinical Trials.

May 23, 2003
IMF Scientific Advisors Lunch Meeting
Working group meeting for our highly esteemed international group of advisors.
Topics: IPI, BOAC, Myeloma Research.

May 23, 2003
International Prognostic Index Presentation
Report of the IMF International Myeloma Working Group
Topics: Methods, Results, Conclusion.

For more information about the IXth International Myeloma Workshop, please visit *www.myeloma.org*. For more details about the International Prognostic Index (IPI), please stay tuned to the next issue of *Myeloma Today*.

IMF HONOR ROLL

The IMF thanks the following individuals for their support of IMF programs and services:

Over $10,000
Gary Takata

Over $1,001 - $5,000
Wade & Kathy Rogers

Over $101 - $250
John Kaplan - $100

Ask the Expert: Staying Well During Chemotherapy

Edith Peterson Mitchell, M.D.

Dr. Edith Peterson Mitchell is a Clinical Professor of Medicine at Jefferson Medical College of Thomas Jefferson University in Philadelphia, and Program Leader of gastrointestinal oncology at Thomas Jefferson University Hospital and Jefferson's Kimmel Cancer Center.

In addition to her clinical responsibilities, Dr. Mitchell is on the board of directors for the International Myeloma Foundation and the Colorectal Cancer Coalition. She is co-leader of Guardcare, a program that provides free physical examinations to inner city individuals. Most recently, she was involved in developing a state-funded, award-winning video about breast cancer, aimed at African-American women. Dr. Mitchell is also a member of a variety of professional associations including the American Society of Clinical Oncology and the American Medical Association.

Dr. Mitchell has been involved in various federally funded research programs. Since 1997, she has been Director of Special Populations for the Eastern Oncology Group, a National Cancer Institute (NCI)-sponsored organization that conducts cancer-related clinical trials. She currently is funded as part of an NCI-sponsored program project grant at Jefferson University Hospital to study genetic changes involved in colon and rectal cancer.

In 2001, Dr. Mitchell became the first African-American to achieve the rank of brigadier general in the Missouri Air National Guard. She is the first female physician to be promoted to this rank in the United States Air Force.

Dr. Mitchell received her Bachelor of Science degree in Biochemistry from Tennessee State University in 1969 and her M.D. from the Medical College of Virginia in 1974. She completed her internal medicine residency at Meharry Medical College and her medical oncology fellowship at Georgetown University in 1977 and 1981, respectively

By Edith Mitchell, MD

When analyzing the challenges of multiple myeloma and the effects of this disease on the lifestyles of patients, it is important to consider all of the surrounding implications of the illness. Not only can multiple myeloma disrupt life with its many emotional, physical, and psychological burdens, but the most common treatments likely will cause a variety of unpleasant side effects. There are strategies, however, that you can adopt in order to help you deal with these side effects.

Chemotherapy is the most widely used treatment for multiple myeloma. Designed to target and destroy cancer cells over a period of time, chemotherapy drugs also often destroy healthy cells. Normal cells that divide the fastest have the highest risk of damage; these are found primarily in hair follicles and the digestive tract. The resulting ill effects such as nausea, vomiting, and hair loss typically are discussed in the doctor's office. But anemia, a frequent and debilitating side effect, often goes unmentioned, even though the majority of patients suffering from myeloma will experience this condition.

Anemia is the lack of an adequate supply of red blood cells. These cells contain hemoglobin, which is used by our bodies to transport oxygen to muscles, tissue and other organs. When our organs do not receive enough oxygen, we feel weakened and exhausted. When chemotherapy destroys red blood cells, the result is extreme fatigue. This type of fatigue is different from exhaustion brought about by activity or stress, which often is relieved by rest or sleep.

Anemia is actually one of the presenting features in multiple myeloma; as the abnormal myeloma cells crowd out the normal cells in the bone marrow, red blood cell production is interrupted. Chemotherapy drugs intended to treat the symptoms of multiple myeloma may also reduce the bone marrow's ability to create red blood cells, leading to a significant drop in hemoglobin levels over time, and increasing the risk of anemia. Together, these two circumstances cause more than 70% of multiple myeloma patients to suffer from anemia.

Strategies for Combating Treatment Side Effects in Multiple Myeloma Patients

Fatigue caused by chemotherapy-related anemia cannot be alleviated through behavioral changes and is constant, making even the smallest daily tasks exceedingly difficult. Extreme fatigue also will prevent you from enjoying life-affirming activities that contribute to your overall sense of well-being and optimism, both very necessary in the battle against multiple myeloma.

Fortunately, chemotherapy-related anemia is often treatable. Your doctor may prescribe a medication to achieve a timely and significant increase in hemoglobin, allowing red blood cells to carry more oxygen and helping restore energy. As the ill effects of anemia subside, you should be able to do many of your daily activities again.

Aside from anemia, there are other serious complications of multiple myeloma that can affect patients. Bone damage and the ensuing pain, renal dysfunction, an inability to fight infection, and hypercalcemia are all possible. Although chemotherapy and radiation often help to control some pain from certain problems, you may need additional supportive care to be comfortable and maintain your quality of life. Pain control medication, relaxation techniques, and positive imagery exercises all are recommended, as is undertaking appropriate physical exercise to stop loss of calcium in the bones, and improve mental outlook. In many cases, a doctor may suggest some changes in diet. A balanced diet provides the vitamins and minerals required to maintain strength and stay active. Good nutrition may actually help in fighting cancer. Food is a great natural source of the energy that your body needs to heal itself.

Along with nutritional balance, emotional wellness will aid in the fight against the devastation of multiple myeloma, chemotherapy and anemia. Participating in pleasurable and relaxing activities such as painting, drawing, and listening to music may reduce stress and offset some of the anxiety caused by living with cancer. Explore all of the ways you can enhance your health and happiness. Even taking a walk or simply spending time with loved ones can contribute to your sense of peace and confidence.

Restoring your energy with the right combination of medication, behavior and activity, can enrich your life and better prepare and motivate you to face the challenges that multiple myeloma presents. There are many ways to feel better. Do not hesitate to ask your physician and other healthcare providers about solutions to the discomfort and fear that you may feel. They are your partners in wellness.

A Complementary Approach: Dr. Shlomit Michaely, Ph.D., L.Ac.

Over the last few months, the IMF Hotline has experienced an increase in the number of questions about complementary approaches to cancer therapy. In response, the IMF Los Angeles Patient & Family Interactive Seminar© has featured a talk by Lewis Mehl-Madrona, M.D., author of *Coyote Medicine*, and *Myeloma Today* has conducted an interview with L.A.-based practitioner Shlomit Michaely, Ph.D., L.Ac..

Myeloma Today: Please tell us about yourself.
Dr. Shlomit: I was born in Jerusalem, and have traveled the world for the last 20 years studying, practicing, and teaching different aspects of the ancient sciences — acupuncture, nutrition, yoga, relaxation, and meditation, to name but a few. I am a graduate of Samra University of Oriental Medicine, licensed by the State of California Acupuncture Committee, and certified as a Diplomat in Acupuncture by the U.S. National Commission for the Certification of Acupuncturists. I hold a Ph.D. in Holistic Nutrition and am the founder of East West Medicine Center. While maintaining two practices in Los Angeles — one with a surgeon at St. Joseph's Medical Center and the other at Y.M.I. Yoga and Wellness Center — I make the time to teach healing yoga, relaxation, and meditation to patients, colleagues, and doctors alike. I also write articles and books and speak at health and well-being conferences.

MT: What is Integrative Medicine?
Dr. Shlomit: Human beings have always suffered from various kinds of disease. Heavy environmental pollution, mental stress, and the increased need for different chemical treatments are but a few of the factors that have given rise to today's heightened awareness and pursuit of Integrative Medicine.

Simply, Integrative Medicine is a combination of several rich and living healing traditions from both Western medicine and Eastern medicine systems of knowledge and practice. Integrative Medicine can transform our view of ourselves into a powerful union of body, mind, and spirit. It has given all kinds of people of all ages and with different conditions — especially chronic ones — new possibilities, choices, and hope for living better, living stronger, and living longer.

MT: How can Integrative Medicine benefit myeloma patients?
Dr. Shlomit: My experience with patients with different kinds of cancer, and other ailments and conditions, has shown me the tremendous benefits of combining the most ancient medicine with the most progressive Western medical treatments available today. As an Eastern- and Western-educated holistic healthcare provider, I bring a combination of complementary philosophies and medicines to my work with myeloma patients undergoing procedures such as chemotherapy, radiation, transplantation, and dialysis. This, combined with my work with a variety of Western medical specialists, has brought about a wider understanding of the specific needs of myeloma patients and the significant improvements they receive from Traditional Chinese Medicine, nutrition, yoga, relaxation, and meditation. This, in turn, has brought about my involvement with IMF.

Shlomit Michaely, Ph.D., L.Ac.
Doctor of Holistic Nutrition and Chinese Medicine

MT: What about acupuncture?
Dr. Shlomit: What is popularly known today as acupuncture and herbal medicine is, in fact, part of the 5,000-year-old complete medical system called Traditional Chinese Medicine, also known as TCM. It emphasizes an integral approach that treats the person as a whole, recognizes patterns of disharmony, and addresses the cause of a disease as well as the symptoms. TCM includes acupuncture, herbs, nutrition, and a variety of ancient energy and physical techniques and exercises.

The acupuncture aspect of TCM is the practice of inserting thin, sterile, disposable needles into the body at specific acupoints. These points are located in a system called the meridians. Mapped by the Chinese over a period of 2,000 years, the meridians are pathways through which the energy of the human body circulates.

According to the traditional theory, in the human body there exists a system of meridians that integrate all of the body's separate parts and functions into a unified organism. As long as the energy flows freely through the meridians, good health is maintained. When the flow of energy is blocked for any reason, there is disruption of health resulting in pain and illness. By stimulating appropriate acupuncture points along the meridians, the energy is released, stimulating internal organs, nerves, bones, blood, and body fluids. Another great advantage of acupuncture is the absence of side effects.

MT: What about the role of nutrition?
Dr. Shlomit: Dietary therapy, specially designed for patients and their constitutions and conditions, provides the basis for maintaining health and treating disease. This fulfills the basic nutritional needs for cell regeneration and production.

MT: Is Yoga another component of Integrative Medicine?
Dr. Shlomit: Yes. Yoga, which means union, is an ancient Indian healing tradition which teaches us how we can enrich, enhance, and extend our lives despite disruption from illness or aging. This long-lived body of knowledge consists of proper exercise, proper breathing, proper diet, proper relaxation, positive thinking, and meditation. According to yoga philosophy, health is not the absence of disease, but a state of balance using mind over matter.

MT: Which myeloma-related conditions can be treated by acupuncture and TCM?
Dr. Shlomit: Acupuncture and TCM can offer benefits in a number of areas:

- *Neurological* — headache, migraine, neuralgia, neuropathy, post-operation pain, and facial pain.
- *Respiratory* — common cold, sinusitis, bronchitis, allergies, asthma, and pneumonia.
- *Digestive* — abdominal pain, intestinal pain, indigestion, hyperacidity, ulcers, diarrhea, and constipation.
- *Musculoskeletal* — pain and weakness, muscle-cramping, joint pain, disc problems, sciatica, broken bones, and bone weakness.
- *Emotional* — insomnia, depression, anxiety, nervousness, and grief.
- *Other benefits* — weight control, stress reduction, strengthening and stabilization of the immune system, side effects of chemotherapy, fatigue, heart problems, gynecological disorders, skin disorders, infections, anemia, and kidney dysfunction.

With all aspects of Integrative Medicine, it is essential to keep in mind the very particular needs of myeloma patients. With every treatment and practice, the emphasis remains on freedom from pain, the strengthening of bodily functions, and increased energy in the body through personalized treatments and practices.

Editor's note: For more information about complementary medicine, please call the IMF Hotline at (800) 452-CURE or visit the IMF website at *www.myeloma.org*. To contact Dr. Shlomit with your questions or inquiries, please visit the IMF website.

BUILDING BRIDGES: Boston Dedicates A New Bridge To Leonard P. Zakim

By Michael Katz

Boston's new Leonard P. Zakim Bunker Hill Bridge is dedicated to the memory of a very special human being who lost his personal battle with multiple myeloma on December 2, 1999, at the age of 46. It is a fitting tribute to a man who dedicated his life to building bridges, working tirelessly for civil rights and intercultural harmony.

The bridge was dedicated on October, 4, 2002 in a moving ceremony attended by about 2,000 people. The ceremony included a multi-ethnic children's chorus assembled for the event, and reached its apex when rock star Bruce Springsteen, whom Lenny had become friends with towards the end of his life, took to the stage to sing his classic, "Thunder Road."

Lenny was co-founder of the Team Harmony Foundation along with former Celtics Assistant Coach and now Deputy Assistant Attorney General for the Department of Justice, Jon Jennings. Jon and Lenny founded Team Harmony after the passing of Celtics Captain Reggie Lewis, whom Jon was close to while coaching the Celtics. Jon and Reggie had wanted to create an event that brought students of all different backgrounds together in a rally to fight hatred and bigotry. To pursue this goal, Lenny came together with Jon and helped found the largest gathering of youth in America to fight hatred and bigotry — Team Harmony. Lenny addressed over 12,000 students from all over New England at Team Harmony VI.

Twin 16-year-old sisters Deena and Shari with their mother Joyce Zakim listen to Bruce Springsteen during the Leonard P. Zakim Bunker Hill Bridge Dedication

Lenny was the Regional Executive Director of the Anti-Defamation League of New England for the last 20 years. He was instrumental in achieving the ADL's mission by being one of the most quoted Jewish civil rights leaders in the region. Lenny was also quick to tend to incidents of hate crimes or violence that affected groups throughout the region, often visiting synagogues that had been desecrated or advising schools that had problems with hate crimes.

He was a noted activist in his efforts to counter bigotry and unite diverse racial, religious, and ethnic groups. He often appeared on radio and television as a Jewish community spokesperson and frequently addressed high school audiences. He published numerous articles on the Middle East, Black/Jewish, and Catholic/Jewish relations, and anti-Semitism; was the author of a Brandeis University publication on coalition building; and wrote a book on anti-Semitism titled Lift Up Your Voice, that was published in the fall of 1998.

Lenny Zakim with his wife Joyce

Lenny served on the Reebok Human Rights Advisory Board and was a member of Harvard's national Black/Jewish working group. He received numerous awards, including the Jewish Community Relations Council's top Jewish professional award, Northeastern University's Human Rights Leadership Award, the National Conference on Christians and Jews Humanitarian Award, and in 1996, he was awarded an honorary degree in humane letters from Brandeis University. In 1997, he received the Urban League's Community Service Award and the Catholic Charities Medal, and in 1998 he received The Wellness Community's Gilda Radner Award. Lenny was honored by Combined Jewish Philanthropies. On a trip to Rome in November, 1998, Lenny was honored with the highest lay honor in the Catholic Church, The Knighthood of St. Gregory, for his work in establishing a greater understanding between Catholics and Jews in the New England region. Lenny was knighted by Pope John Paul II.

In Lenny's own words: "I had a really good life. And the diagnosis of cancer was the end of that life as I knew it. Being told you have cancer is still, I think, the three worst words you can hear in your entire life. When you're diagnosed with cancer, you are stripped of titles, you're stripped of previous power, ideas of power, illusions of control. Cancer is a disease that doesn't just affect your body, it affects your mind, it affects your soul, it affects your heart. It affects every relationship you have. I found that you want to try to wage a full scale mobilization of resources to deal with this disease. That's why it's important in the process of treatment to do something — whether it's acupuncture, vitamins, more water, changing your diet, massage, guided imagery, or music therapy."

Lenny's passion for complementary therapies bore fruit on November 27, 2000, when the Dana-Farber Cancer Institute opened the Leonard P. Zakim Center for Integrated Therapies. The center provides complementary therapies to patients and their families, offers education on complementary therapies to patients, families, and staff, and advances knowledge of effectiveness and outcomes of these therapies through peer-reviewed, evidence-based clinical research.

Lenny Zakim is survived by his wife Joyce, daughters Deena and Shari, and son Joshua.

Ferreting for Facts in the Realm of Clinical Trials

The IMF has licensed the use of Jane Brody's article for *Myeloma Today*. It first appeared in the *New York Times* on October 15, 2002.

By Jane E. Brody

Millions of women discovered a basic in medicine, much to their dismay, this summer when the Women's Health Initiative study showed that postmenopausal hormone replacement did not prevent heart attacks. Only clinical trials, they learned, can establish a definitive fact about the effectiveness and safety of a diagnostic technique, preventive method, or treatment.

Experience with patients in doctors' offices and hospitals and observational studies like the Nurses' Health Study can offer hints, sometimes strong ones, on benefits and risks of various procedures and habits, but they are still only guesstimates.

Turning a hint into a hard-to-refute fact requires a clinical trial in which participants are randomly assigned to one procedural group or another. Even then, the findings can be applied with certainty only to the kinds of people or circumstances used in the trial.

Lifesaving Progress

Clinical trials are the backbones of medical progress. They have demonstrated the value of vaccines to prevent devastating diseases and drugs to treat them. They have shown, for example, that certain drugs given immediately after a heart attack or stroke can markedly increase survival while others do not help. And clinical trials are behind nearly all the progress that has been made in treating various kinds of cancers in the last four decades.

Treatments that now save the lives of most children with acute leukemia and most young adults with Hodgkin's disease were established through clinical trials. So was the replacement of radical mastectomies, the standard therapy for breast cancer for more than half a century, with lesser procedures like simple mastectomies and, more common now, lumpectomies followed by radiation therapy and sometimes chemotherapy.

The newer therapies are not only less damaging to a woman's body and self-image but are also associated with better survival rates. Thanks largely to the findings of clinical trials, the five-year survival rate for all stages of breast cancer is nearing 84 percent, and rates for melanoma and cancers of the cervix, uterus, prostate and bladder exceed 90 percent.

Yet, only 3 percent to 5 percent of cancer patients take part in clinical trials, which test standard therapies against new approaches that may or may not be better than the standard. It usually takes three years to enroll enough patients in a cancer trial to produce statistically significant results, a simple fact that delays progress in the fight against cancer.

Why More Don't Participate

Misconceptions about the nature of clinical trials, along with insurance hurdles, contribute to the reluctance of many cancer patients to join clinical trials and, often, their doctors' reluctance to suggest that they participate. Cancer Care, a national organization at (800) 813-4673 that offers free education and support for cancer patients and their families, attributes this reluctance mainly to a lack of information and fear of research.

Many people fear that participating means they will be guinea pigs who could receive dangerous treatments that would make things worse, not better. But before patients are enrolled in clinical trials, the treatments have undergone several preliminary tests. After laboratory tests and animal studies show promising results, new treatments go through two tests in patients.

The first, a Phase 1 study, involves a small number of patients (maybe a dozen or two) who cannot be helped by other known treatments. In this phase, researchers look for the best way to administer a new treatment, how it can be used safely, and if there may be harmful side effects.

Please see next page

Indiana University Cancer Research Center Patient Dinner

Dr. Rafat Abonour and Oncology Nurse Gina Smith

Dr. Rafat Abonour, Oncology Nurse Gina Smith and other members of the Indiana University Cancer Research Center organized a patient dinner in Indianapolis on October 17th, 2002. There was quite a crowd, with more than 150 patients and caregivers in attendance. This was the second annual patient dinner for the folks in Indiana, where there are not yet any myeloma support groups.

Invited speakers included Dr. Kenneth Anderson of the Dana Farber Cancer Institute and Mike Katz from the International Myeloma Foundation.

Dr. Anderson presented an overview of current research in myeloma. While the briefing was a bit technical, the overall message is clear — there is a lot of very exciting work going on in understanding the biology of myeloma that is opening up new ways to approach treatment of the disease.

Mike Katz discussed lessons learned as a patient in the twelve years since his diagnosis. The attendees were very engaged in the discussion, asking some very good questions and sharing some of their own war stories.

People stayed well past the end of the program to take advantage of the opportunity to talk to others battling myeloma. We salute Dr. Abonour, Gina Smith, and the dedicated staff from the Indiana University Cancer Research Center for all of their hard work. We also thank Celgene, Novartis, and Amgen for their support of this very important patient event.

Gloria and Timothy Hortsmeyer with IMF Board Member Mike Katz

Dear Reader – continued

of Leeds, UK) and Dr. Brian Van Ness (University of Minnesota, USA). Co-Chairs for the IPI are world experts in myeloma, Dr. Jesus San Miguel from the University of Salamanca, Spain, and Dr. Phil Greipp from the Mayo Clinic, USA. Both of these outstanding projects will greatly benefit patients in the short term and long term. The possibilities are endless.

The results of the IPI project will be presented at the IXth International Myeloma Workshop in Salamanca, Spain on May 25th from 1:30PM to 3:30PM. Work on BOAC is just beginning and we'll have more to report in the upcoming months. Both of these projects embody the spirit and innovation that is the IMF; they are collaborative efforts of over 20 research centers around the world. The IMF has always been about people helping people, families helping families. Now we can also say we're about researchers helping researchers.

If you would like to learn more about these projects and would like to become a Supporting Partner, please contact the IMF.

Susie Novis
President

Clinical Trials – continued

Next, a Phase 2 trial involves perhaps 100 patients, looking for a treatment benefit. In the case of a cancer drug, for example, does it shrink the tumor? Is it less damaging than existing therapies?

Finally, comes the big Phase 3 trial involving hundreds and perhaps thousands of patients around the country. In it, the new treatment is compared directly with standard therapy. At this point, patients are randomly assigned to groups taking the new therapy or the old one.

Patients may not be told which treatment they are receiving and sometimes the doctors who care for them do not know until the trial ends. This is to avoid bias, the unintentional exaggeration of the benefits or risks of the new therapy.

Before patients are enrolled in clinical trials, they must be told in detail, orally and in writing, what it will involve. Then, they are asked to sign informed consent forms that fully describe the studies and their potential risks and benefits.

Patients are not obligated to complete the study, and they can drop out at any time for any reason. If too many leave, however, the study findings may have no validity.

In the course of a study, the safety and effectiveness of the treatment being tested are independently monitored. If at any point it appears to be less effective or more hazardous than the standard — or if the new therapy is far better than the standard — the trial will be discontinued.

This is precisely what happened with the Women's Health Initiative study. Once the risks of hormone replacement were found to exceed a certain preset level of safety, the trial was prematurely ended.

Benefits and Risks

At the very least, by joining a clinical trial, you will receive the best established therapy. At most, you will be among the first to receive a treatment that proves to be better, either more effective or less hazardous. All participants in clinical trials also receive high-quality care and are likely to be closely monitored and tested to assess their progress.

For those with an altruistic bent, trial participants also have the opportunity to help others through improved treatments that then become widely used. This is exactly what happened as a result of the breast cancer treatment trials.

You do not necessarily have to live in the vicinity of a major cancer center to participate in a cancer treatment trial. More and more community hospitals are getting involved, and in some cases the financing covers transportation to a trial center.

To be sure, there can be drawbacks to trial participation. As the National Cancer Institute points out in its excellent booklet, "Taking Part in Clinical Trials: What Cancer Patients Need to Know": "New treatments under study are not always better than, or even as good as, standard care. They may have side effects that doctors do not expect or that are worse than those of standard treatment."

Even if a new treatment proves to be better than the standard, it may not work for every patient.

Then there is the medical insurance issue. Some providers refuse to cover the costs of what they view as experimental treatment.

While study participants are not charged for the remedy being tested (which can costs hundreds of dollars for each treatment), they are usually responsible for all ancillary costs. It is best to check with your insurer to find out what will be covered before you decide to take part in a clinical trial.

Find out, too, just what participation will involve, including the kinds of tests that will be done and how often, where treatment will be administered and for how long, who will be in charge of your care, whether your own doctor will be involved, and if there will be follow-up care or tests after the study has ended.

IMF Calendar

March 5-7, 2003
National Dialogue on Cancer Public-Private Partnership Meeting
Washington, DC

March 21-22, 2003
IMF Patient & Family Seminar
Little Rock, AR

April 6, 2003
Fashions 4 A Cure
Lancaster, NY

April 7-8, 2003
OVAC Advocacy Days
Washington, DC

April 9-13, 2003
SWOG Group Meeting
San Diego, CA

May 1-3, 2003
ONS Annual Meeting
Denver, CO

May 17, 2003
4th Annual JC Invitational Golf Tournament
Sauk Rapids, MN

May 23-27, 2003
IX International Myeloma Workshop
Salamanca, Spain

May 31 - June 2, 2003
ASCO Annual Meeting
Chicago, IL

June 5-7, 2003
ECOG Group Meeting
New Orleans, LA

June 15, 2003
"Hair Cares" MM Fundraiser
Glen Mills, PA

June 27-29, 2003
IMF Support Group Leaders' Retreat
Durham, NC

June 30, 2003
Bob Canter Golf Tournament
Stamford, CT

August 2, 2003
Dr. Robert A. Kyle Award Dinner
Rochester, MN

October 1-5, 2003
SWOG Group Meeting
Seattle, WA

October 4, 2003
Ribbon of Hope - Making a World of Difference Anniversary Gala
Seattle, WA

September 27-28, 2003
IMF Patient & Family Seminar
Heidelberg, Germany

November 7-8, 2003
IMF Patient & Family Seminar
Dallas, TX

November 15-17, 2003
ECOG Group Meeting
Miami, FL

December 5-9, 2003
ASH Annual Meeting
San Diego, CA

For more information, please check the IMF website at www.myeloma.org or call the IMF at (800) 452-CURE.

News & Notes

FUNdraising Made Easy

The IMF's new FUNdraising program is designed to assist our members with their fundraising activities. Deciding on a fundraising event and bringing it to fruition can be a confusing task, but the IMF is here to provide you with the tools, the assistance, and the expertise you need to make your FUNdraising a success. For over 12 years, the IMF has been successfully working with members of the myeloma community from around the world, helping to produce special events to raise money for myeloma research and education programs. It's fun and easy to do and you'll have the satisfaction of knowing that you have made a difference. No idea is too large or too small. The IMF wants to give you every opportunity to do something for your community. Please call Suzanne Battaglia at (800) 452-2873 or email her at *SBattaglia@myeloma.org*. She is awaiting your call, ready to answer your questions and to make suggestions about how you can get involved.

Young IMFer wins 4-H First Prize

Cotton Canfield has won first prize at the Oconee County (Georgia) 4-H contest for her presentation entitled "Living with Mulitple Myeloma." Cotton's grandmother, Frances Love, is a myeloma survivor. Cotton, who is 10 years old, spent part of her Christmas vacation helping to take care of her Grams in Cincinnati. So, when it was time to pick a topic for her presentation, she chose one very close to her heart. Using materials from the Atlanta IMF Patient & Family Seminar, she developed five posters and an informative discussion on what myeloma is, what causes the disease, how it is treated, the impact it has on people affected by it, and what others can do to help. Cotton stressed the importance of supporting the IMF, getting involved with myeloma advocacy and awareness, and offering emotional support to patients. Cotton will repeat her "Living with Mulitple Myeloma" presentation at the District competition. She also held a fundraiser in honor of her grandmother and has donated the proceeds to the IMF.

The Art of Healing

On November 13, 2002, members of the cancer community took paintbrushes in hand to transform a blank canvas into a life-affirming mural. This New York City event kicked-off the *Art of Healing: Expressions of Cancer Survivors* national campaign sponsored by Ortho Biotech Products, L.P. The final mural has been included in a collection of online greeting cards designed especially for people living with cancer and featuring artwork created by patients during their battle with cancer. These cards will be available free of charge throughout 2003 at *http://greetings.yahoo.com/cards/art-of-healing*.

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