OCTOBER 2003 VOLUME 5 NUMBER 8

MYELOMA TODAY

A PUBLICATION OF THE INTERNATIONAL MYELOMA FOUNDATION

INTERNATIONAL MYELOMA FOUNDATION
EDUCATION•RESEARCH•SUPPORT•ADVOCACY
"Until There is a Cure... There is the IMF."

HIGHLIGHTS

This issue of
Myeloma Today
is supported by
Millennium Pharmaceuticals

SALUTING AN INCREDIBLE HUMAN BEING: *Dr. Robert A. Kyle* *Receives Lifetime Achievement Award*

By the Unknown Patient

Dr. Robert A. Kyle with IMF President Susie Novis and IMF Board Chairman Dr. Brian Durie

Rochester, Minnesota is perhaps best known as the home of the Mayo Clinic. Most people to whom myeloma is not Unknown also know that Rochester is home to Dr. Robert A. Kyle. Dr. Kyle has been a leader in the scientific community, a beloved physician caring for myeloma patients for longer than the Unknown Patient can remember. When the Unknown Patient heard that the IMF was going to honor Dr. Kyle with its first ever "Robert A. Kyle Lifetime Achievement Award," he knew he had to pack his Unknown bag and head for the heartland. Your Unknown traveler was joined by people who came to Rochester from every corner of the country with a single purpose in mind—to pay tribute to this warm, wonderful, talented, accomplished human being.

Arriving in Rochester in August, your Unknown friend encountered something he never thought possible in Minnesota—heat and humidity. The Unknown Patient took advantage of the opportunity to consult with a number of physicians at Mayo about some orthopedic issues related to surgery he had over a decade ago. Mayo is an incredible institution, with some of the world's best physicians and an infrastructure that runs like a well-oiled machine but still manages to preserve the human touch.

There was also time for a little recreation. The Unknown Patient was able to visit the Olmstead County Fair with fellow IMFers, Rich and Sue Saletan, making the acquaintance of all manner of livestock, horticulture, cooking, and crafts. Your Unknown author was possessed with an irresistible urge to ride on the tallest and most stomach-wrenching of the carnival rides, which no doubt would have prompted horrified looks from his spouse and his orthopedist.

Having survived the excursion to the fair, the Unknown Patient showered away the scent of the livestock and the ravages of the August heat and put on his party duds for the gala. Guests were offered a tour of the Mayo Myeloma Research labs before the dinner. Needless to say, this was an opportunity not to be missed. So, the Unknown Patient headed off to get a rare peek behind the scenes of one of the world's most prolific myeloma research facilities.

Mayo luminaries Drs. Philip Greipp, Vincent Rajkumar, and Rafael Fonseca led the group through the facility. The group then had the

Please see next page

DR. KYLE – *continued*

opportunity to meet with Dr. Morie Gertz and other members of the "team that Kyle built." They discussed a number of promising research programs and answered questions about the facility and about future research directions. It was a rare opportunity to get an up close and personal view of the relentless quest for the cure, a chance to see how the research dollars we all help raise are put to good use.

From there, it was off to the Rochester Marriott for the evening's festivities. The pre-dinner reception was a festive event, with all manner of folks chatting up a storm and taking the opportunity to meet and greet the honoree and his lovely family. The Unknown Patient met many old friends and many others who had come from near and far to join us in honoring Dr. Kyle. The Unknown Patient found three long-term myeloma survivors in the crowd, two out past twelve years and one who was diagnosed over seventeen years ago.

Out of the corner of his eye, your Unknown shutterbug spied the evening's honoree having an intense chat with a sweet-looking woman whom it turns out was married to one of his patients. Apparently, this woman is also a very talented artist. And, she had painted a portrait of Dr. Kyle that she presented to him to honor him on this special occasion. IMF president Susie Novis presented Dr. Kyle with a leather bound copy of the Gala Tribute Journal, acknowledging Bob's lifelong interest in collecting rare stamps and books.

Dr. Kyle inspects his likeness as artist Geraldine Fineman looks on

The reception also afforded an opportunity to meet the Kyle clan, most of whom were Unknown to this author before that evening. It was fun to tell them how much we all love him.

Dr. Morie Gertz served as emcee for the evening, sharing many personal memories and stories about our honoree. There were jokes about Bob's predictable wardrobe and lunchbox contents, but the overall message was one of profound admiration and respect for the man who built the Mayo's world class Hematology service and Myeloma Research Center. Other speakers included Drs. Brian Durie and Philip Greipp, both of whom have worked with Dr. Kyle over a number of decades. IMFer Mike Katz provided the patient

Please see page 4

(top row) Drs. Martha Lacy, Angela Dispenzieri, John Lust, Jerry Katzmann, Diane Jelinek, and Vincent Rajkumar
(bottom row) Philip Greipp, Robert Kyle, Morie Gertz

INTERNATIONAL MYELOMA FOUNDATION

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

Founder
Brian D. Novis

President
Susie Novis

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

Kelly Cox
kcox@myeloma.org

Suzanne Battaglia, Special Events
sbattaglia@myeloma.org

Nancy Baxter, Hotline Coordinator
nbaxter@myeloma.org

Debbie Birns, Hotline Coordinator
dbirns@myeloma.org

Michele Cherney, Exec. Asst. to Ms. Novis
mcherney@myeloma.org

Spencer Howard, Meeting & Event Services
showard@myeloma.org

Marya Kazakova, Publications Editor
mkazakova@myeloma.org

Kemo Lee, Subscriptions & Merchandise
klee@myeloma.org

Carole Menacker, Support Group Liaison
cmenacker@myeloma.org

Lisa Paik, Information Officer
lpaik@myeloma.org

Myeloma Patients and Oncology Nurses to Benefit from IMF/Millennium Collaboration

The IMF and Millennium Pharmaceuticals, Inc., of Cambridge, MA, the developer of VELCADE™ (*bortezomib*) for Injection, (*a novel agent approved in the United States on May 13, 2003 by the FDA*) have agreed to collaborate on a medical education initiative for oncology nurses nationally which will also benefit multiple myeloma patients in their care. For the full prescribing information go to *www.mlnm.com/products/velcade/index.asp*).

Through an unrestricted educational grant provided by Millennium, the IMF will work with oncology nurses to develop a series of accredited continuing education (CE) initiatives of interest to oncology nurses. A number of States require nurses to accumulate a minimum number of CE credits each year, enabling them to stay current on the latest and most up to date treatments within their field. This series of CE accredited initiatives will help oncology nurses nationally achieve this goal as well as assist them in the care and treatment of their patients with multiple myeloma.

As part of this collaboration, the IMF will use nurses from the Millennium AdvoCare Speakers Bureau. AdvoCare is sponsored by Millennium and is comprised of nurses and other medical professionals who have experience in working with VELCADE to treat multiple myeloma patients.

"We are very excited about this collaboration with Millennium," said Brian G.M. Durie, M.D., IMF Chairman of the Board. "Through this collaboration, oncology nurses can access valuable medical education resources to assist them in caring for multiple myeloma patients."

A listing of these initiatives will be featured on a web-hosted portal accessible through the IMF website. These medical education initiatives will initially include the following:

- CE accredited presentation entitled: Proteasome Inhibition: A Novel Option for the Treatment of Multiple Myeloma Patients;
- CE-accredited Roundtable discussion featuring oncology nurses discussing frequently asked questions (offered from both the nursing and patient perspectives);
- CE-accredited case study section which will present a series of interesting nurse oriented cases dealing with the care and treatment of multiple myeloma patients.

Local Support Groups will also have the opportunity to work with the Advocare nurses as speakers at their local meetings by contacting the IMF and requesting a nurse. In addition, IMF Patient & Family Interactive Seminars held throughout the country will also be able to utilize the AdvoCare nurses as speakers during their sessions. For a current listing of upcoming events, please visit the IMF website at *www.myeloma.org*. Through a phone call, an oncology nurse experienced in the care and treatment of multiple myeloma patients can be identified, selected, and arrangements made for the nurse to be a part of a local or regional activity. Please contact the IMF for additional information.

Millennium and the IMF are also exploring the possibility of conducting an Oncology Nurse CE session at each Regional Patient & Family Interactive session.

"The IMF is proud to be involved in this collaborative effort with Millennium," said Susie Novis, IMF President. Improving the quality of life of myeloma patients and helping them in their struggle against their disease is the main mission of our organization. This partnership with Millennium will enable oncology nurses from across the country to become more educated about appropriate multiple myeloma patient management, which will directly translate into better patient care."

VELCADE is indicated for the treatment of multiple myeloma patients who have received at least two prior therapies and have demonstrated disease progression on the last therapy. The effectiveness of VELCADE is based on response rates. There are no controlled trials demonstrating a clinical benefit, such as an improvement in survival. ❧

The IMF Visits Italy and France

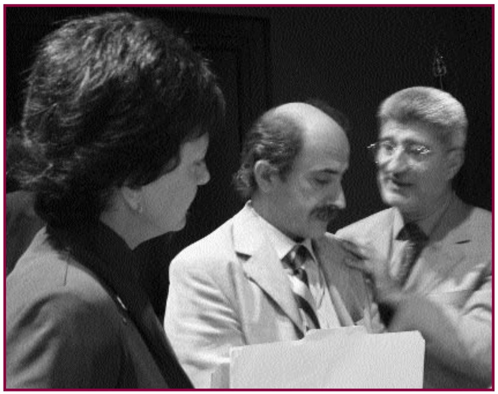
Barbara Schulz, Susie Novis, Dr. Jean-Luc Harousseau, and Dr. Brian Durie at the Paris IMF Patient & Family Seminar

Under the auspices of the IMF, IMF Scientific Advisors and distinguished Professors Mario Boccadoro and Jean-Luc Harousseau held the first ever IMF Patient & Family Seminars in their respective countries. IMF President Susie Novis greeting over 200 people at the Torino meeting on September 12th, and over 130 in Paris on the 19th.

Because the concept of medical meetings for patients and their families is a novel one in France and Italy, the IMF received an enthusiastic response from both the patient and medical communities, and there was press coverage at both seminars. We were particularly touched when the medical director of the hospital in Torino addressed the audience, telling them that the seminar was more than a sharing of medical information; it was an important ethical and humanitarian step. The IMF, he said, had opened the pathway to better communication between all patients and their doctors in Italy.

The distinguished faculty in Italy, in addition to Dr. Boccadoro,

Please see page 4



IMF Hotline Coordinator Debbie Birns with Dr. Marco Gobbi and Dr. Mario Boccadoro

DR. KYLE – *continued*

perspective, sharing memories of his first encounter with Dr. Kyle as a Mayo clinic patient. Mike also talked about their many years working together on the IMF Board, at IMF Patient & Family Seminars, as well as at many scientific community conferences. Dr. Jerry Katzmann of the Mayo Clinic also saluted Bob's distinguished career at the Mayo Clinic and congratulated him on receiving the IMF award.

IMF president Susie Novis presented Dr. Kyle with an award established and named in his honor—The Robert A. Kyle Lifetime Achievement Award. Susie read the inscription from the award, "In appreciation and recognition of a lifetime of dedication, caring, and accomplishment, on behalf of the patient, medical, and scientific communities, the International Myeloma Foundation is proud to present its first Robert A. Kyle Lifetime Achievement Award to Robert A. Kyle, M.D., Professor of Medicine and Laboratory Medicine Mayo Clinic."

The Unknown Patient has been fighting his personal battle with myeloma for almost fifteen years now. Due to the efforts of talented scientists like Dr. Kyle, the team that he has built, and the profound effect he has had on myeloma research around the globe, the outlook has never been brighter for myeloma patients. There are exciting new therapies available that did not exist a few short years ago. And, there are an unprecedented number of new therapies in clinical trials and still others being tested in the laboratory.

We thank Dr. Robert A. Kyle for being such a caring physician and for his dedication to advancing myeloma research to bring us closer to the cure. Bravo, Bob! ❧

Char and Bob Kyle surrounded by family and friends

ITALY & FRANCE – *continued*

included Dr. Brian Durie (ably translated by Dr. Bruno Benedetto, who studied for four years at the Fred Hutchinson Cancer Center and now heads the allo transplant team in Torino), Dr. Marco Gobbi, Dr. Maria Petrucci, Dr. Patrizia Tosi, and Dr. Antonio Palumbo. Dr. Boccadoro and his able staff organized and publicized the seminar, which took place at the hospital of Saint John the Baptist. Dr. Boccadoro was interviewed on the TV news before the seminar because it was considered a revolutionary idea in Italy to conduct a medical meeting for cancer patients rather than cancer doctors. It is sometimes difficult not to take patient seminars for granted in the US. We have to remind ourselves that they were revolutionary here, too, when the IMF initiated the concept in 1993.

At the Paris seminar, the eloquent French faculty who joined Drs. Durie and Harousseau included Drs. Thierry Facon, X. Mariet and J.P. Fermand. On an extremely warm Friday without air conditioning, we were fortunate to be offered relief in the beautiful

Please see page 10

EARLY STUDIES INDICATE TARGETED RADIOACTIVE DRUG MAY EXPAND TREATMENT OPTIONS FOR MYELOMA

Gregory Wiseman, M.D.
Nuclear Medicine Specialist
Mayo Clinic
Rochester, Minnesota

Angela Dispenzieri, M.D.
Hematologist
Mayo Clinic
Rochester, Minnesota

By Gregory Wiseman, M.D.,
and Angela Dispenzieri, M.D.

The ultimate goal of cancer treatment is to rid the body of every malignant cell so the patient has the best chance for a very good or complete remission.

For more than two years, we have been conducting phase I and II clinical studies with that goal in mind. Our focus: to learn whether combining a targeted radioactive drug with high-dose chemotherapy can enhance the prospect of wiping out all of the destructive myeloma cells without increasing risk to the patient. While it's still too early to pass final judgment, we are encouraged by the results we've seen to date.

Our studies have involved the drug Quadramet; its technical name is "153-samarium EDTMP." Quadramet belongs to a new class of drugs that target radiation directly to bone and spare the rest of the body from exposure. The drug was approved by the Food and Drug Administration (FDA) several years ago for easing pain resulting from cancer spread to bone. It consists of a radioisotope, or radioactive atom, wrapped inside a molecule that binds very tightly to bone. The radioisotope is 153-samarium – an atom whose nucleus contains a total of 153 protons and neutrons – and the wrapper is EDTMP (ethylene diamine tetramethylene phosphonic acid), which binds to bone.

We know myeloma cells are sensitive to radiation. Indeed, until about five years ago, combining chemotherapy with whole-body radiation from an external source was standard practice in myeloma patients undergoing stem-cell transplantation. But the toxicity from chemotherapy combined with whole-body radiation caused more damage to normal organs. So radiotherapy was dropped from the treatment regimen.

The current treatment for myeloma recommends chemotherapy administered intravenously to reach wherever cancer cells may be hiding. To boost the odds that no cancer cell will survive, very high doses of chemotherapy drugs are used. Side effects may result because the chemotherapy drugs target not only cancer cells, but also all fast-dividing cells. Especially vulnerable are the all-important bone marrow blood producing cells that reside in bone marrow and serve our circulatory, blood clotting and immune systems.

To prevent that destruction while still hitting cancer hard, many otherwise healthy myeloma patients undergo a procedure called bone-marrow stem-cell rescue. Stem cells are removed from the patient by a special IV, then frozen and stored. After the patient has completed the chemotherapy treatments, the stem cells are intravenously infused back into the patient to begin the process of producing healthy blood cells.

There is no question that stem-cell transplantation improves a myeloma patient's chances of survival. But unfortunately, almost every transplant patient eventually suffers a relapse. The most likely reason for the relapse is that the high-dose chemotherapy given before the stem-cell transplantation failed to kill all the myeloma cells in the patient's bone marrow.

Now a new class of radionuclide therapy drugs that targets radiation to specific sites of cancer in the body is being developed. Quadramet is one of the new targeted radiation drugs. Its availability is causing researchers to look again at the use of radiation for treatment of myeloma.

With Quadramet, molecules that do not bind to bone are rapidly excreted. This means levels of unwanted radioactivity delivered to the rest of the body remain low and do not damage organs or other parts of the body where there is no cancer. The drug has an excellent safety record when used for treating pain from other cancers spread to bone. Its chief side effect is that at high doses it tends to deplete bone marrow cells. Interestingly, this drawback could be a plus for myeloma therapy because our aim is to kill diseased bone-marrow cells before intravenously reinfusing the patient with his or her own stem cells to make new, healthy bone-marrow and blood cells.

In early 2000, we began a phase 1 clinical study to determine how much Quadramet we could give patients without further harming their bone marrow. We treated 12 myeloma patients with increasing doses of Quadramet. The regimen was basically the same for all patients: after undergoing bone-marrow stem-cell collection, each patient received a 30-minute infusion of Quadramet. Twelve days after that, each patient got an approximately 60-minute infusion of the standard dose of melphalan (the chemotherapy drug most commonly used for transplantation of myeloma). Then two days later, each patient received intravenously his or her own

Please see page 8

VETERANS, AGENT ORANGE, MULTIPLE MYELOMA, AND VA BENEFITS

Tom Courbat
U.S. Army Vet 1968-1969

By Tom Courbat

ELIGIBILITY FOR MAJOR VA BENEFITS

I was diagnosed with multiple myeloma two years ago after suffering excruciating pain in my lower back for the entire summer of 2001. I couldn't figure out why I was having such pain and the X-rays and CAT scans revealed nothing significant. It wasn't until the doctor reviewed the blood test results 1/2 hour before surgery that he suspected I might have myeloma. Following surgery and a biopsy, the diagnosis was confirmed. I lived with it for the first year and a half always wondering how I might have been exposed to something that could have caused this, as I was relatively young (54) and was in reasonable physical health. I had worked in executive government positions since leaving the military without exposure to toxic substances.

In March of 2003, on the MM listserv (*www.acor.org/myeloma.html*), a wonderful woman, Taura King, wrote in stating that veterans with MM who were exposed to Agent Orange (AO) were potentially eligible for a vast array of Department of Veterans Affairs (VA) benefits. I figured that since I was in Korea, and knew nothing about spraying of AO there, that I would not qualify and figured it would be a waste of time to apply. Boy, was I wrong – and thus begins the good news for many veterans with MM.

WHAT MIGHT YOU BE ELIGIBLE FOR?

- Disability compensation up to $2,500 per month or more, tax free and separate & apart from Social Security Disability benefits!
- Free medical, dental, and vision at VA facilities
- Free prescriptions
- Free medical coverage for your spouse and dependents through CHAMPVA
- Free access to military BX, PX, and commissaries (with no sales tax)
- Waiver of vehicle licensing fee (varies by state)
- Reduction or elimination of property tax obligation (varies by state/county)
- Access to military recreation and lodging facilities at reduced charges
- Educational benefits for yourself (if not already used) and your dependents
- $10K life insurance if health issues limited to VA disability; possible paid premium
- Free burial in military graveyard with free headstone
- Waiver of 2% fee for VA home loan
- Special Disabled parking privileges (varies with state/county)

HOW/WHY MIGHT YOU BE ELIGIBLE?

For those stationed in Viet Nam, even if only there for one hour, the VA grants "presumptive eligibility"; that is, one does not have to demonstrate exposure or connection between AO and MM. If you fall into the following categories where the military has ADMITTED spraying or testing AO, there is a reasonably good chance you will qualify for up to a 100% disability rating from the VA. What is required frequently depends upon the regional office and/or the service officer involved in reviewing your claim.

- Soldiers who served on or near the Korean demilitarized zone (DMZ) in 1968 and 1969
- Soldiers stationed at Fort Drum, NY in 1959 (testing).

Other areas where veterans allege AO to have been sprayed include:

- Guam from 1955 through 1960s (spraying).
- Johnston Atoll (1972-1978) was used for unused AO storage.
- Panama Canal Zone from 1960s to early 1970s (spraying).

The military has NOT admitted AO use in the above three locations and thus filing a successful disability claim is much more problematic for those who were there. It is also noted that AO has a half-life of as much as several decades, as noted by the diseases still being experienced by Vietnamese citizens today who farm land sprayed with AO back in the '60s and '70s and who drank the water it was polluted with. Again, however, getting the VA to agree that you contracted MM due to the continued contamination of AO if you served in Korea in the '70s for example is problematic. I'm not sure anyone has been successful in that endeavor.

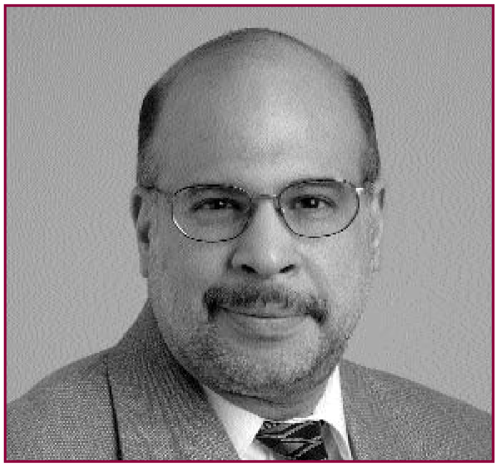
HOW TO APPLY AND WHAT TO EXPECT

Get a rep from the Viet Nam Vets of America (yes, they WILL help other vets exposed to AO), American Legion , Veterans of Foreign Wars, or Disabled American Vets to represent you. They know a lot more about this than most of us individually, and they don't charge a dime to help you. If you call and they DON'T know about this, call another group! The admission about spraying in Korea only came about a couple of years ago, and is not widely publicized. For more information on the disability compensation programs of the VA, go to *www.va.gov* and click on "Compensation."

The process can take up to 18 months. Mine took only 4 months, and you might be fortunate too. You can help speed the process by providing extensive documentation of your military assignments, your current medical condition and doctors' statements, and a list of your OTHER medical conditions that are a result of MM or the treatment for MM (e.g. peripheral neuropathy, erectile dysfunction, depression, anxiety, sleep apnea).

A list of resources to aid in this process can be found on my homepage at *www.caringbridge.org/ca/tomcourbat*. I hope this is of help to our myelomic veterans.

ASK THE EXPERT: *The use of DOXIL® in multiple myeloma*



Mohamad Hussein, M.D.
Director, Myeloma Research Program
Cleveland Clinic Taussig Cancer Center
Cleveland, Ohio

DOXIL® (pegylated liposomal doxorubicin) is an advanced form of doxorubicin. Unlike conventional doxorubicin therapy, Doxil is a liposomal formulation that is encapsulated in a thin fatty layer. The liposome is pegylated, which helps protect the drug from the immune system, resulting in the product circulating in the blood for a longer period of time. Although Doxil is commercially available, it is not currently specifically approved for myeloma. There are several ongoing trials to further delineate the use of Doxil in myeloma. More widespread use of Doxil will depend upon the trial results.

Myeloma Today: Are there new studies that highlight the use of Doxil in the management of multiple myeloma?
Dr. Hussein: Yes, there are several trials. There is, for example, the national multi-center trial, involving over 200 patients, comparing Doxil, Vincristine, and decadron (DVd) versus Vincristine, Adriamycin, and Dexamethasone (VAD). This study has completed accrual and towards the end of this year, or early next year, we should have the results available. At this stage, it looks promising.

MT: What advantages do you see, or hope to see, in DVd versus the standard VAD?
Dr. Hussein: Ease of use and reduced toxicity. The aspect that I am most interested to see is if the response and the durability are any different from VAD. The first DVd cycle is usually three hours. After that, it can be given over one and a half to two hours. And the steroids are only for 4 days, not 12 days as in the VAD protocol. If we can have a less toxic regimen that is easier to give on an outpatient basis, and patients' overall performance status can stay maintained, that would be a big deal.

MT: Do you see DVd replacing VAD as an induction for stem cell transplantation?
Dr. Hussein: I do. I think the reason for that is that it doesn't impact the normal cells of the bone marrow negatively, it's a quick outpatient regimen, and it does not have the steroid toxicity that occurs with VAD. Infection is therefore less of an issue. I think those are the things that make this regimen relatively easy. And if [doctors] are interested in preparing their patients for transplant, this is a regimen that can get them there without a whole lot of toxicity. That's my impression. I'm hoping that this multicenter trial confirms this information.

MT: How long does it take a myeloma patient on DVd to get into remission?
Dr. Hussein: On average, a response occurs by the second cycle. Patients tend to reach maximum response after 5 cycles. If they don't respond by cycle 2 or 3, they usually don't respond. But 5 cycles seems to be the magic number for maximum response.

MT: What place do you see for DVd in frontline therapy?
Dr. Hussein: I think it's going to be in combination with thalidomide or with Revimid. We recently completed a trial with DVd and thalidomide (DVd-T). We presented preliminary data in ASH, ASCO, and Salamanca. Hopefully, in the upcoming ASH meeting, we will present a more complete therapy data of over 100 patients. And I think this is where the combination (DVd) will be positioned – in combination with an immunomodulator.

MT: So, in myeloma, you see DVd fitting in with novel therapies?
Dr. Hussein: Absolutely. Unlike VAD, our preliminary results show that DVd does get rid of the abnormal blood vessels in the bone marrow. However, the duration of the responses were not positively impacted probably because we were not able to maintain the clearance of blood vessels. Novel therapies like Revimid and thalidomide don't get rid of the abnormal blood vessels but they maintain the status. So, if Doxil gets rid of the abnormal blood vessels and those other drugs maintain the status of it being gone, then I think you could make an impact on the disease overall. This is what I am hoping to be able to show with DVd-T. And we've started a DVd-Revimid trial.

MT: Does DVd have a place for relapse?
Dr. Hussein: Not by itself – the response has been disappointing, about 20% to 25%. But when you combine it with thalidomide, the response rate is a really impressive 75%, with 45% of those patients either CR (complete remission) or near CR. So, I would say that DVd-T definitely does have a place. Some people would say that because you can get responses with decadron-thalidomide only, why add Doxil and vincristine? Because I think that the quantity of the responses is better and the quality of the responses is definitely better. With decadron-thalidomide in relapse/refractory, you may get only 5% CR and few near CRs.

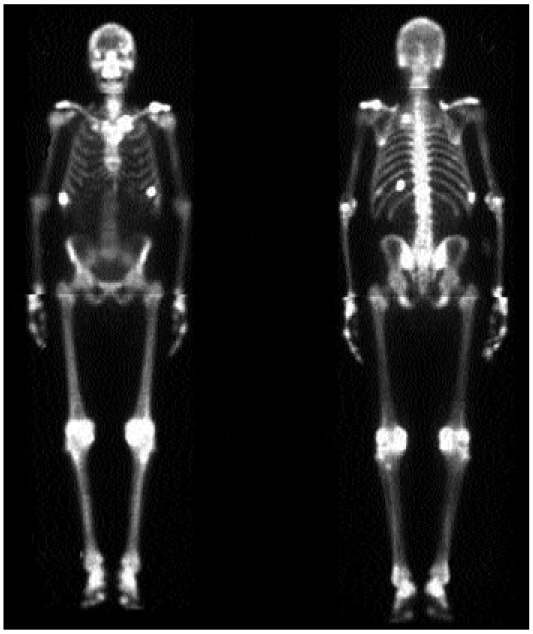
MT: What is the dosing in the DVd-T combination?
Dr. Hussein: We use doxorubicin (40 mg/m^2), vincristine (2.0 mg IV), and oral or intravenous dexamethasone (40 mg/day x 4 days) every 4 weeks. We start thalidomide at 50 mg/day, increasing by 50 mg/day every week to the maximum tolerated dose not to exceed 400 mg/day. We also add amoxicillin (which we are now thinking is probably not necessary) and acyclovir to reduce infection; low-dose aspirin in an effort to reduce blood clotting problems and so far this has worked very well for us.

MT: How does a Doxil side effect such

Please see page 8

QUADRAMET – *continued*

stem cells. This reinfusion procedure took about 15 minutes to a half-hour. Patients were monitored throughout the entire process for toxicity and to confirm that the newly transplanted cells had started functioning in the bone marrow.



We found that giving Quadramet plus standard chemotherapy before stem-cell transplantation produced no greater toxic effects than chemotherapy and transplantation done without radiotherapy. This successful outcome prompted us to proceed to our phase II study, which involved 46 patients.

Because every patient absorbs and metabolizes drugs somewhat differently, for our phase II study we gave each patient an individually measured amount of Quadramet. The dose level was based on "test dosing" to determine how much Quadramet each patient should have to safely target the same radiation to the bone marrow in each patient.

In both studies, patients were evaluated 100 days after their stem-cell transplants for evidence of residual myeloma. Our goal was to see at least 50 percent of the patients achieve either a complete response or a very good partial response. We're pleased to report that we appear to be seeing that outcome.

Both our phase I and phase II studies are now completed and all of the data will be evaluated later this year. Then we will have more statistically valid evidence about the use of Quadramet for treatment of myeloma.

At this juncture, we know that Quadramet given prior to melphalan chemotherapy does give significantly more treatment to the myeloma cells than with the chemotherapy alone and currently we have not seen any additional toxic effects. Our measurements verify that the radiation delivered by Quadramet to organs other than bone was well within safety limits.

While we're enthusiastic about the promising indications, we want to temper our enthusiasm with this caution – these are early results. More research through a randomized phase III clinical study needs to be conducted to conclusively determine the value of Quadramet for treatment of myeloma. Hopefully, future studies will substantiate these early results and take us another step forward in our efforts to combat myeloma, help patients live longer and improve the quality of their lives. ❧

Note: Quadramet is a product of Cytogen, Inc.

DOXIL – *continued*

as the palmar-plantar erythrodysesthesia (PPE) syndrome – swelling and pain of the extremities – impact quality of life?

Dr. Hussein: The PPE is more of an education issue. When we first started using the regimen, 4 out of our first 9 patients had severe PPE. What we learned was that without patient education, patients were not careful in the first few days with touching, repetitive movement, and pressure areas. With education, our incidence of PPE is down to about 7%, and we've treated about 300 patients with the regimen without any particular prophylaxis other than the education.

MT: What about other side effects, such as anemia and neutropenia?

Dr. Hussein: That has not really been an issue for us. In over 200 patients, we have not had a patient admitted because of neutropenic fever. We have not seen any issues with thrombocytopenia requiring transfusion. We have not had to resort to any drastic measures that we tend to do with regular chemotherapy like VAD, for instance.

MT: What are the most frequently occurring side effects with DVd?

Dr. Hussein: With DVd regimen by itself, it's the drop in the white counts. I would say leukopenia, not neutropenia. The count drops but the patients are not necessarily neutropenic. That's pretty much it. PPE is about 7%, hair loss is less than 5%, nausea and vomiting is less than 5%, transfusions related to platelets is zero, and infections requiring IV antibiotics has not been an issue. With this being said, we aggressively follow patients and teach them to avoid infectious problems. For instance, if patients qualify, we use intravenous immunoglobulins, and early in URI we use oral antibiotics. When you combine Doxil with thalidomide, the toxicity can be significant but we've modified the regimen, adding some supportive care drugs, like Neulasta and Procrit, and we've done really well with that. So what started as a problematic regimen with the thalidomide addition, now is a very straightforward regimen to use.

MT: What about the impact on a patient's quality of life?

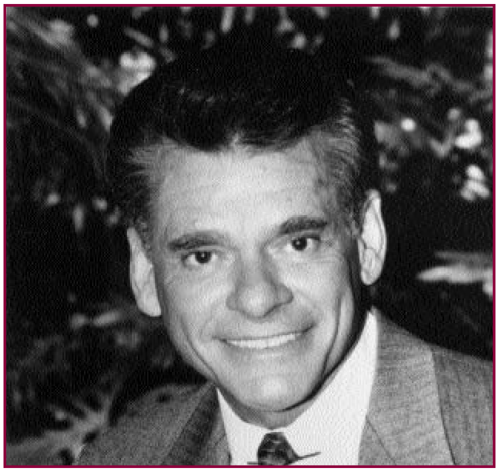
Dr. Hussein: I would say that the quality of life is definitely better. But you are talking to someone who is biased – we developed the regimen.

MT: Any closing comments?

Dr. Hussein: I think that the regimen is moving forward in combination with other drugs, like thalidomide and Revimid. At ASH 2003, we should have a major update on DVd in combination with thalidomide. And in combination with Revimid, I would expect some results by ASCO 2004. ❧

Note: For additional information about Doxil-based regimens in the management of multiple myeloma, please see Dr. Hussein's report in the *IMF Salamanca Guide*. This guide can be obtained by calling the IMF at (800) 452-CURE (2873).

IT'S YOUR ATTITUDE… IT'S YOUR CHOICE



Tom Bay, Ph.D.

By Tom Bay, Ph.D.

For over thirty years, I have been in the professional speakers business. I've written three books, appeared before 500 companies, and had over 6,700 speaking engagements. I've never had to work a day in the past thirty plus years. My dad was right: "Find something to do that you love and you'll never work again."

The core material in my book and my talks is based on attitude. In fact, the tag line for my company is "It's Your Attitude… It's Your Choice." Little did I know how important this statement would become in my personal life. I've asked audiences over and over again to answer the following questions: Whose life is it? Who's responsible for it? What do you plan on doing about it? And last question… When?

Six years ago I was diagnosed with prostate cancer and the answers to these questions became much more significant to me. And none of these questions could be answered until I recognized what I had control over and what I did not control. It seemed so easy from the lecture platform. What do you control? What don't you control? Now that my life was at risk, thoughts of my family, loved ones, grand kids, and my business, etc. etc, were all spinning in my head. Combine these thoughts with the anger of "why me?" I did all the right things: exercise, diet, rest… and the doctor interrupted my thoughts with one very enlightening statement. "Tom, cancer doesn't care." This slapped me back into focus. I had been spending more time on things I had no control over and very little time on what I really controlled. I checked out all the offered solutions, asked lots of questions, and made the decision to have the seed implants. I checked into the hospital at 1:30 p.m., had the procedure at 4:00 p.m., and checked out of the hospital at 8:30 p.m. that same day. My attitude had taken control: I did not choose to be a member of this "club" but my reaction was my choice. I had a life to live. Things were going great. My PSA numbers dropped and I was cancer free.

Two years later, I was given another opportunity to walk my talk. I went to see my doctor for what I thought was a week-long bout with the flu. I walked into his office for my 2 o'clock appointment, looking forward to my blood test results. My doctor followed me into the patient room. He asked five questions in quick succession, to which I answered "yes" in each case. Then the bomb dropped. He told me I had complete renal failure and I must go immediately to the hospital for dialysis of my kidneys. Less than two hours later, I was having the impurities in my system being mechanically removed. Two days later, they gave me the news that my kidney had failed because I had multiple myeloma. "Doc, I don't have time for cancer," I said, "What are we going to do now?" His response I will never forget. "Tom, I like your attitude." Little did I know that the prostate cancer was just a test run for my attitude towards myeloma.

I want to live life, not exist. The more I talk with other cancer patients, the more I am convinced that attitude has a major impact on each and every one of us as we face each day. Starting with the recognition of what events we don't control and what events we have control over. Reach out, grab the events that you can control and do the best you can to adapt to the ones you don't control. You and I are too important not to take control of our destiny, as best we can under the circumstances. We are in a club that none of us chose, with a membership we cannot cancel. Our attitude impacts all we do and affects all those around us. Attitude is the little thing that makes a big difference. Right or wrong, good or bad, positive or negative, It's Your Attitude… It's Your Choice. Make it a great day by making a great choice. ❧

LETTERS

IMF PATIENT & FAMILY SEMINAR

Thank you for the outstanding work you do towards making the lives of all us who have MM better. Once again, you did a remarkable job of putting on a Patient & Family seminar in Atlanta. As much as I get out of those, it's my wife, Sheila, who benefits the most. You session "caregivers need care too" is what she attends those seminars for.

Greg Robinson
Georgia

IMF HOTLINE

The International Myeloma Foundation is a thoughtful and necessary support group for patients with multiple myeloma. The IMF was there when I needed information on the disease, and continues to provide me useful support, every step of the way. Yesterday, I called the IMF Hotline and asked for a referral to a hospital and doctor in the San Francisco area, as our family will be moving to the East Bay. Nancy Baxter handled my inquiry and gave me some contact information, but then said she wanted to research this further. Nancy took the initiative to contact Dr. Brian Durie for his suggestions, and called back to give me additional contacts. I am so appreciative to Nancy and your organization for being there. Thank you all.

Steve Igo
Connecticut

SUPPORT GROUP LEADERS CONFERENCE CALL

Thank you for the opportunity to take part in such a informative and helpful teleconference. Dr. Durie was excellent and it was exciting to hear about the latest research and advances. I can't wait to share the information with my support group.

Sue Sumpter RN, MS
Oregon

Thanks so much for hosting this call which provided us all with up to the minute information. I sincerely appreciate the time and effort you all devote to keeping us informed. I shared the information with our support group that met the same night and we had a great discussion. Thanks to all who made the call possible.

Vicki Anderson
Florida

IMF CALENDAR

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

October 4, 2003
Ribbon of Hope - Making a World of Difference
IMF's 13th Anniversary Gala
Seattle, WA

October 17-18, 2003
IMF Patient & Family Seminar
Philadelphia, PA

October 23-26, 2003
Christmas at the Fair
Whaton, IL

November 1-2, 2003
IMF Patient & Family Seminar
Tokyo, JAPAN

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

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

November 16, 2003
Fiesta for the Cure
Los Angeles, CA

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

January 23-24, 2004
IMF Patient & Family Seminar
Ft. Lauderdale, FL

March 18-19, 2004
IMF Patient & Family Seminar
Minneapolis, MN

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

MYELOMA AT THE MOVIES LENDING LIBRARY

The IMF is pleased to bring our Patient & Family Seminars to people around the country who might not be able to attend an actual meeting. We have set up a video lending library of a variety of presentations and question and answer sessions. The IMF will continue to expand the library by videotaping future seminars and key talks!

Tape 1: KYPHON Procedure for Myeloma (Dr. Jean Valory)
Tape 2: Supportive Care & Complications of Bone Disease (Dr. Philip Greipp)
Tape 3: Novel Therapies (Dr. Brian Durie)
Tape 4: High Dose Therapy & Stem Cell Therapy (Dr. Sundar Jagannath)
Tape 5: Myeloma 101 & MGUS (Dr. Robert Kyle)
Tape 6: Approach to Newly Diagnosed Myeloma & Conventional Therapy (Dr. Vincent Rajkumar)
Tape 7: Part I – After any Diagnosis (Carol Svec, RN)
Part II – Charting Your Numbers (Michael Katz)
Part III – Senate Hearing (Susie Novis)
Tape 8: Management of Bone Disease (Dr. Brian Durie)
Tape 9: Standard Therapy for Myeloma (Dr. Robert Kyle)
Tape 10: Overview of Myeloma and an Update on Amyloidosis (Dr. Morie Gertz)
Tape 11: High Dose Therapy and Transplantation (Dr. William Bensinger)
Tape 12: Patient Testimonials (John Schwartz and Richard Dennison)
Tape 13: VELCADE™ for Injection Procedure
Tape 14: Standard Therapy for Myeloma (Dr. Brian Durie)
Tape 15: Overview of Myeloma & Update on Amyloidosis (Dr. Morie Gertz)
Tape 16: Novel Therapies with Focus on VELCADE™ (Dr. Jeffrey Wolf)
Tape 17: Update from the Intergroupe Francais Myelome (Dr. Jean Luc Harousseau)
Tape 18: Management of Bone Disease (Dr. Robert Vescio)
Tape 19: Alternative Healing (Dr. Lewis Mehl-Madrona)
Tape 20: The Binding Site (Anne Grainger, RN)

If you are interested in borrowing a videotape from our library, please call Paul Hewitt at the IMF. The IMF lends the tapes out one at a time. A credit card number is required to borrow a tape, and your card will be charged $25 if you lose or forget to return the tape within 30 days. Otherwise, there is no charge. ❧

ITALY & FRANCE – *continued*

formal gardens behind the building, which were open to seminar attendees throughout the day. Even more beautiful was our special guest, the French actress Barbara Schulz, friend of the IMF and daughter of a cancer patient. Barbara most graciously interrupted her filming in the south of France to attend the seminar and lend support to the myeloma patients and their families. We owe very special thanks as well to Morgane Yvon, whose mother is a patient of Dr. Harousseau's. Morgane created a beautiful poster, publicized the seminar by mail and Internet, communicated with all the prospective attendees, and has sent each of them our newly updated French educational booklets.

A heartfelt *grazie* and *merci* to Celgene and Novartis, who helped make these ground-breaking seminars possible. We look forward to working again with Drs. Boccadoro and Harousseau on behalf of the wonderful patients in Italy and France, and hope that these two successful seminars were just the beginning. ❧

News & Notes

Susan and Bob Haaz

HAAZ FAMILY EVENT A SUCCESS!

On August 3, 2003, the Haaz Family – Susan, Aaron, Jeff, and Meredith – met friends at their home and walked a mile in honor of Susan's husband, Bob, who passed away on August 30, 2002, after a courageous battle with myeloma. The walk culminated in a lovely breakfast at a nearby restaurant and everyone agreed that Bob would have been pleased at the turnout and enthusiasm with which his friends and family participated in this first-time event. They raised over $5,000 in Bob's honor to benefit IMF programs.

NEW MM SUPPORT GROUP IN AUSTRIA

A new multiple myeloma support group has been established in Austria, with Ilse Hein and Doris Mayerboeck sharing responsibilities for the group. Several other patients and one caregiver are assisting with this venture. Joerg Brosig of the myeloma support group in Germany, and Henk Mittendorf of the myeloma support group in Switzerland, have also lent their support. Our thanks to our friends in Austria, Germany, and Switzerland and special thanks to Prof. Heinz Ludwig.

MILE HIGH MARCH FOR MYELOMA

Friends, family, townspeople from neighboring communities all gathered in Lake Arrowhead on August 16 to celebrate Myeloma Awareness Week. In fact, there were walkers from as far away as Washington State, Oregon, San Diego, and San Francisco. The event was organized by Arrowhead resident Lisa Doyle, in honor of her father, Ed, who has myeloma. The day consisted of a walk through the village, raffles, performances by the local troupe from the Arrowhead Dance Studio and the Church of the Woods Worship Band. All proceeds from the event were donated to the IMF, and plans are already underway for next year's walk. ❧

ORDER FORM

		quantity:
One Year Subscription to *Myeloma Today* (US)	$_____ (*donation*)	________
One Year Subscription to *Myeloma Today* (Int'l)	$_____ (*donation + $15.00*)	________
Back Issues of *Myeloma Today* (each)	$ 3.00 £ 5.50	________
Myeloma Today Anthology I:		
Transplantation for Multiple Myeloma	$ 3.00	________
Myeloma Today Anthology II:		
Articles of Continuing Interest	$ 3.00	________
Comprehensive Guide to Banff	$_____ (*donation*)	________
Going for the Cure		
by Dr. Francesca M. Thompson	$11.50 £ 7.00	________
Audio Tapes 2003 Atlanta Patient Seminar	$35.00	________
Audio Tapes 2003 Los Angeles Patient Seminar	$35.00	________
Audio Tapes 2002 Seattle Patient Seminar	$35.00	________
Audio Tapes 2002 Chicago Patient Seminar	$35.00	________
Audio Tapes 2002 Dallas Patient Seminar	$35.00	________
WAM 2000 Syllabus Books	$40.00 (*while supplies last*)	________
IMF Logo T-Shirt	$12.00 £10.00	________
IMF Baseball Cap	$15.00	________
Shipping & handling (International orders only)	$ 3.85 £2.50	________
Donation to the IMF	$_____ £_____	________
Total:	$_____ £_____	________

**** All payments to the IMF originating outside the U.S. must be charged to a credit card.***

We accept checks, money orders, and AmEx/VISA/MasterCard. Please make checks payable to **IMF** *or* **IMF (UK)**

AmEx/Discover/VISA/MasterCard: ____________ ***Expiration:*** ________

Name as it appears on card: ____________ ***Telephone:*** ________

Forward completed order form to:

IMF Headquarters
International Myeloma Foundation
12650 Riverside Drive, Suite 206
North Hollywood, CA 91607-3421 USA
Tel: (800) 452-CURE
(818) 487-7455
Fax: (818) 487-7454
E-mail: *The IMF@myeloma.org*

UK Office
International Myeloma Foundation
31 York Place, 2nd Floor
Edinburgh EH1 3NT United Kingdom
Tel: (44) 0800-980-3332
(44) 0131-557-3332
Fax: (44) 0131-556-9720
E-mail: *TheIMF@myeloma.org.uk*

ORDER FORM

International Myeloma Foundation
12650 Riverside Drive, Suite 206
North Hollywood, CA 91607-3421 U.S.A.

www.myeloma.org
(800) 452-CURE (2873)

Address Service Requested

NON-PROFIT
ORGANIZATION
U.S. POSTAGE
PAID
PERMIT NO. 665

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