



**INSIDE THIS  
ISSUE**

Welcome  
Letter

PAGE 2

New at the  
Foundation

Page 2

Time Inc.  
Tribute

Page 3

Medical  
Corner

Pages 4, 5

You Need  
to Know

Page 6

Immune  
Therapy  
Symposium

Page 7

Industry  
Partners

Page 7

Honor a  
Friend

Page 8

# MYELOMA FOCUS

Newsletter of the Multiple Myeloma Research Foundation

## Neiman Marcus Selects MMRF to Host Escada Fashion Show All Funds Support Research

**T**he Multiple Myeloma Research Foundation (MMRF) was chosen by Neiman Marcus to premiere Escada's Fall Collection, on Monday, May 3, 1999. The MMRF was selected



L-R: Dru Pyne, Manager Public Relations, Neiman Marcus, Bob Devlin, V.P., General Manager, Neiman Marcus, Carol Wolf, Fashion Show Chair

from among hundreds of worthy organizations across the country to participate in the first showing of the new line. Join us for cocktails, hors d'oeuvres and an evening of incredible New York runway fashion. Only two hundred guests will be able to share in this evening of glamour and excitement, so order your tickets now! General admission is \$75 and, preferred seats, \$125 per person. Contact Carol Wolf at (914) 251-0716 for ticket information and volunteer opportunities. All ticket proceeds will fund multiple myeloma research.



## MMRF Funds Promising Vaccine Research



Dr. Anders Österborg

**A**dvances in technology have increased the potential for development of an effective vaccine against myeloma.

Dr. Anders Österborg, of Karolinska

Hospital, Sweden, and Dr. Freda Stevenson, of Southampton University, UK, are Multiple Myeloma Research Foundation award recipients and tell us about their progress.

Immune therapy is one of the many areas the MMRF funds.



Dr. Freda Stevenson

(See their interviews pages 4 and 5)

## Myeloma Team **pushes for government support**

**A** strong team met with the Healthcare Financing Administration (HCFA) and the National Cancer Institute (NCI) in Washington, DC, to take a stand for multiple myeloma patients. The goal was twofold: (1) To ask HCFA to approve autologous stem cell transplants for Medicare patients meeting protocol criteria, and (2) to generate awareness and support for multiple myeloma at the NCI.

Kathy Hill, a registered nurse and patient advocate, presented extensive legislative research. Ann Traynor, MD, Director of the Multiple Myeloma Research Lab at Northwestern, presented compelling clinical data, and Kathy Giusti, MMRF President, provided analyses on myeloma incidence, mortality

(Continued page 3)

# Welcome Letter

**D**ear Friends,

All of us have met special people along the way, as we fight our battle with multiple myeloma. We find people who fight with such courage and determination, people who amaze us with their positive attitude. For me, that was my friend Eileen Ottenheimer who passed away on Thanksgiving Day 1998, at age 38. The MMRF office was flooded with beautiful notes, and donations for research, from her friends and family. This serves as a testimony to the inspiration Eileen passed on to so many of us.

Mike Ottenheimer, Eileen's husband, reflected that "Eileen viewed the disease as chronic rather than fatal" and that she pursued every treatment option available to her. "She was very involved with her own treatment" and she viewed this involvement to be "as important as the medicine." Throughout her courageous 8-year battle with multiple myeloma, Eileen never lost hope. Empowered with the love and support of her husband, family and friends, Eileen helped establish the "Believe" support group in October 1997, in an effort to help others fighting multiple myeloma. Mike Ottenheimer wishes the readers to know that "the MMRF is very needed...the funds go to the right place and are used efficiently."

Eileen's passing has had a lasting impact on all of us. Her final words to me were "keep up the good work kiddo." The loss of Eileen Ottenheimer underscores the importance of MMRF's mission to push harder, and move faster, in the search for the cure.

*Kathy Aivisti*

## You can help Accelerate the search for a cure

- Thank a friend with our beautiful Acorn Pin - an order form is on page 8.
- Provide a donation in the enclosed envelope, and ask your company about "matching funds."
- Ask your company to sponsor our "Fall Gala"- we can take care of any necessary correspondence.
- Call us if you have an item for our live, silent auction - travel packages are greatly appreciated.
- Provide names of friends or family members who might want to receive Myeloma Focus.
- Call us if you have a specific skill or contacts that could support our efforts (eg. printing or public relations).

*Donations to the MMRF can be sent to*  
**MMRF**  
**11 Forest Street,**  
**New Canaan, CT 06840**



Eileen  
Marie Jeanne  
Schoenfeld Ottenheimer.

People like Eileen push us harder and faster to find a cure. Our special thanks to those who contributed to the MMRF in her name.

## New at the Foundation

### Jenny McMahon

Director of Event Planning. Jenny will be responsible for the Foundation's fundraising events and programs. Jenny brings extensive experience in community service and event planning. She holds a Masters Degree in Education.

### Ellen Kaplan

Assistant Development Director. Prior to joining the MMRF, Ellen served as Manager of Client Relations for the Matching Gift Center in New York.

### Nancy Scranton

Volunteered to manage the MMRF's volunteer efforts. Nancy will be responsible for overseeing our 100 volunteers who help with administrative needs and fundraising events.

## New on MMRF Scientific Advisory Board

A special welcome to our new scientific advisors

**Jean-Luc Harousseau, M.D.**

University Hospital, Nantes, France

**Heinz Ludwig, M.D.**

Wilhelminenspital, Austria

*A Special Thank You*  
to the following  
corporations for helping support

### Myeloma Focus:

G.D. Searle

Novartis

Ortho Biotech

Grey Healthcare Group

Nexell Therapeutics

Printer:

King Lithographers and Mailers

## Myeloma Team pushes for government support

(Continued from page 1)

rates and funding trends. Cathy Callahan, daughter of a Medicare patient who died of myeloma, provided a personal perspective.

Dr. Grant Bagley, HCFA Director, presented Medicare's concerns about national reimbursement. Dr. Traynor and Kathy Hill addressed his concerns and raised awareness of the disparity between the treatment coverage provided by Medicare, and that provided by other carriers such as Medicaid. Dr. Bagley provided clear guidelines for the next step - a written inquiry to the newly formed HCFA Advisory Committee. The issue is now on the HCFA radar screen with the inquiry quickly forthcoming.

Kathy Giusti presented the disparity in myeloma funding in meetings with Congressman Bilirakis' office, and Dr. Alan Rabson, Deputy Director of the National Cancer Institute. Both groups were alarmed by the high mortality rates of myeloma. Dr. Rabson identified clear opportunities for the Multiple Myeloma Research Foundation (MMRF) and NCI to collaborate and generate increased support for the disease. A follow-up meeting will be held next month.



At NCI Headquarters in Washington, DC (from L-R) Cathy Callahan; Kathy Hill, RN; Dr. Allan Rabson, Deputy Director, NCI; Kathy Giusti, President MMRF; Ann Traynor, M.D.

## Time Inc. Delivers Time and Again



(Top L-R) Robin Shallow, Dir. Relations, SPORTS ILLUSTRATED; Michael Klingensmith, Pres., SPORTS ILLUSTRATED; Art Berke, V.P. Communications, SPORTS ILLUSTRATED; Lauren Kaiser, Art Director Creative Services, SPORTS ILLUSTRATED; Alvaro Saralegui, Group Publisher, PEOPLE Magazine; Christine Rosa, Athletic and Team Relations, SPORTS ILLUSTRATED; (Bottom L-R) Karen Andrews, Assoc. Gen. Counsel, Time Inc; Cleary Simpson, Publisher, SPORTS ILLUSTRATED for Kids; and Frankie Whelan, Dir. Events & Special Projects, PEOPLE Magazine.

**K**ey to the success of the MMRF's efforts is the willingness of individuals and organizations to donate their valuable time, resources, and talent. **Time Inc.** has supported the MMRF from the start providing financial support and contributing extensive resources from the talented and tireless staff of its many magazine divisions.

Karen Andrews, Associate General Counsel for **Time Inc.** (who founded the MMRF with her twin sister Kathy Giusti), said *"I am so privileged to work for a corporation that includes so many diversely talented people so willing to contribute their services, from public relations, to celebrity contacts, to corporate donations."*

**SPORTS ILLUSTRATED**, has not only generously provided financial support as a benefactor of the Fall Gala - it has also provided significant corporate resources. Michael Klingensmith, President of **SPORTS ILLUSTRATED**, said *"SPORTS ILLUSTRATED is proud to muster resources to the cause"* and plans to continue to help in their efforts. Lauren Kaiser, Art Director of Creative Services for **SPORTS ILLUSTRATED**, designed the logo for the MMRF, as well as the extensive printed materials required for the Fall Gala. She has also recruited *"an entire team of graphic design volunteers who are committed to the Foundation."* Christine Rosa, Athletic and Team Relations, uses her many sports contacts to obtain memorabilia and event tickets to help raise funds for research. Christine remarked how fortunate she is to have **Time Inc.** behind her to help support the fundraising efforts of the MMRF. As a result, the Fall Gala includes a unique auction featuring one of a kind sports items from Muhammad Ali's boxing gloves, to a "New York Fan Day Package" comprised of tickets to each of the major New York sporting events. Alvaro Saralegui, Group Publisher, **PEOPLE Magazine**, has successfully introduced notable people to the Foundation who have become involved in the Foundation. He is a long-time friend and colleague of Karen Andrews, and remains committed to supporting the Foundation.

We would also like to thank Robin Shallow, Art Berke, Cleary Simpson, Frankie Whelan and so many other kind and committed people at **Time Inc.** who graciously contribute their time, talents and resources to the MMRF. The MMRF extends its gratitude and honors to each and every one.



# Medical Corner

Dr. Anders Österborg

## MMRF funds research in the development of an idiotypic vaccine against multiple myeloma

*Dr. Österborg, please tell us about your research on an idiotypic vaccine against multiple myeloma.*

We are trying to develop an idiotype vaccine that will control minimal disease during the early, indolent or smoldering phase of multiple myeloma. Currently, we are trying to determine what effect the use of certain growth factors (cytokines) has on the immune response when used with an autologous idiotypic vaccine. We have done three series of immunizations in a total of 14 patients with myeloma who had received no other treatment. In our first series, five patients with multiple myeloma were immunized with the patient's myeloma protein (M-protein) alone. A specific T cell response against the patient's M-protein was induced in two of these patients, but the response was modest and of short duration.

In our second series, we immunized five patients with smoldering multiple myeloma using their own M-protein. In addition to the vaccine, this second series of

patients also received the cytokine GM-CSF for 4 days. We repeated this same immunization procedure 2,4,6,8, and 14 weeks later. In all 5 patients, our laboratory analysis showed that a specific T-cell response against the patient's own M-protein was induced. The magnitude of this response was greater and seemed to last longer than in the patients who did not receive the cytokine GM-CSF. In one of these patients, the M-component concentration was reduced by 65%. Four more patients have been immunized in this way, but results are not yet available.

### *Are there other situations when this idiotype vaccine might be used?*

An idiotype vaccine may be useful in patients in clinical remission following high dose chemotherapy when the number of myeloma cells would be low. The purpose of giving the idiotype vaccine would be to suppress the emergence of any remaining myeloma cells.

*How long do you estimate it will be before an effective idiotype vaccine against myeloma is available for routine use?*

If we can get tumor cells to decrease, we can expect this strategy to be part of routine patient management within a few years. If the vaccine merely stabilizes the disease, we would have to await results from comparative trials that would compare the vaccine with existing therapy to determine if our therapy provides any advantages.

*Dr Österborg, is there anything about your research that you would like to add?*

I think it is important to point out that we do not yet know if idiotype vaccination will be a successful tool to control minimal disease during the early, indolent phase of the disease. However, based on findings by Dr. Kwak and coworkers in low grade lymphoma, which like myeloma is a B cell tumor, we are very optimistic that idiotype vaccines may induce clinical effects in patients with myeloma.

### Cancer Vaccines

- The body's immune system recognizes and fights invading organisms (antigens). When an antigen enters the body, it is recognized as foreign and an immune response is produced that destroys the antigen. This immune response involves many types of cells and compounds (cytokines).
- The immune system remembers its first encounter with an antigen and reacts more quickly and effectively when it encounters that antigen again. Vaccines are based on this ability of the immune system to remember and respond more quickly and effectively.
- Cancer cells are not easily recognized as foreign and the normal immune response does not occur. The goal of a cancer vaccine is to increase the immune response against cancer cells (antigens) and to have the body remember and repeat this response each time it encounters a cancer cell.

### Idiotypic Vaccines

- Immunoglobulins (antibodies) are proteins. Because they are proteins they can serve as antigens. An autologous idiotypic vaccine uses part of the patient's own immunoglobulin as the antigen in the vaccine. The M-protein is a specific part of the immunoglobulin produced by each individual with multiple myeloma.

- Cytokines, compounds that enhance the immune response, are produced by cells in the body. The body produces numerous cytokines, including IL-12 and GM-CSF. Many cytokines are produced commercially for medical use. Combining a vaccine with substances, such as cytokines, may increase the immune response.

### DNA Vaccines

- DNA is like a string of pearls with each pearl being a gene. In humans, these DNA strings, called chromosomes, contain several thousand genes. Each gene is encoded with a message for a specific product, often a protein.
- The DNA of a DNA cancer vaccine encodes for a protein (antigen) that the body's immune system recognizes as a protein of the tumor cell. This causes an immune response that is remembered. When the tumor cell protein is encountered again on the tumor cell, the body remembers the immune response and responds quickly and effectively against the tumor cell. To further increase the likelihood that the protein will be recognized by the immune system, an alert signal may be included in the vaccine. This alert signal attracts cells that patrol the body looking for antigens.

# Dr. Freda Stevenson

## MMRF and the McCarty Cancer Foundation fund development of a DNA vaccine

*Dr Stevenson, please tell us about your research on a DNA vaccine against multiple myeloma.*

Our goal is to develop a DNA vaccine that will help suppress the growth of any myeloma cells that still exist (residual tumor cells) in a patient who has achieved remission. Our approach is to use a "genetic" (DNA) vaccine that contains genes that act as a code for the production of tumor specific proteins. When an individual receives this DNA vaccine, the body reads the genetic code in the vaccine and then produces that specific tumor protein. These proteins then act as the vaccine antigen. The body's immune system responds against this tumor protein (antigen) and that immune response is remembered.

However, tumor proteins are weak and usually do not activate an immune response. Therefore, our DNA vaccine also contains a gene that codes for a danger alert signal. This signal alerts the cells that patrol the body looking for antigens such as bacteria. Now alerted, these patrol cells recognize the tumor antigen and signal the body that a immune response is needed.

*What do you foresee as the greatest challenge in the development of an effective DNA vaccine against myeloma?*

Two major challenges exist. The first is to design a DNA vaccine that will induce the greatest immune response possible, great enough to suppress tumor growth. We are making excellent progress in this area. The second challenge is to ensure that patients retain or regain the ability to generate an immune response, which means that treatments such as chemotherapy will have to take into account the need to retain or restore the immune system.

*Why is an alert signal needed?*

The alert signal is necessary for two reasons. First, tumor antigens, such as myeloma cells, are not readily recognized by the immune system, which is the reason they continue to grow and multiply. Our alert signal is highly attractive to cells that patrol the body looking for pathogens such as bacteria. Second, a patient who has had tumor for some time is likely to be immunologically tolerant to tumor antigens. This means that the particular T cells, which direct the immune response, may be ineffective. Our alert signal uses a

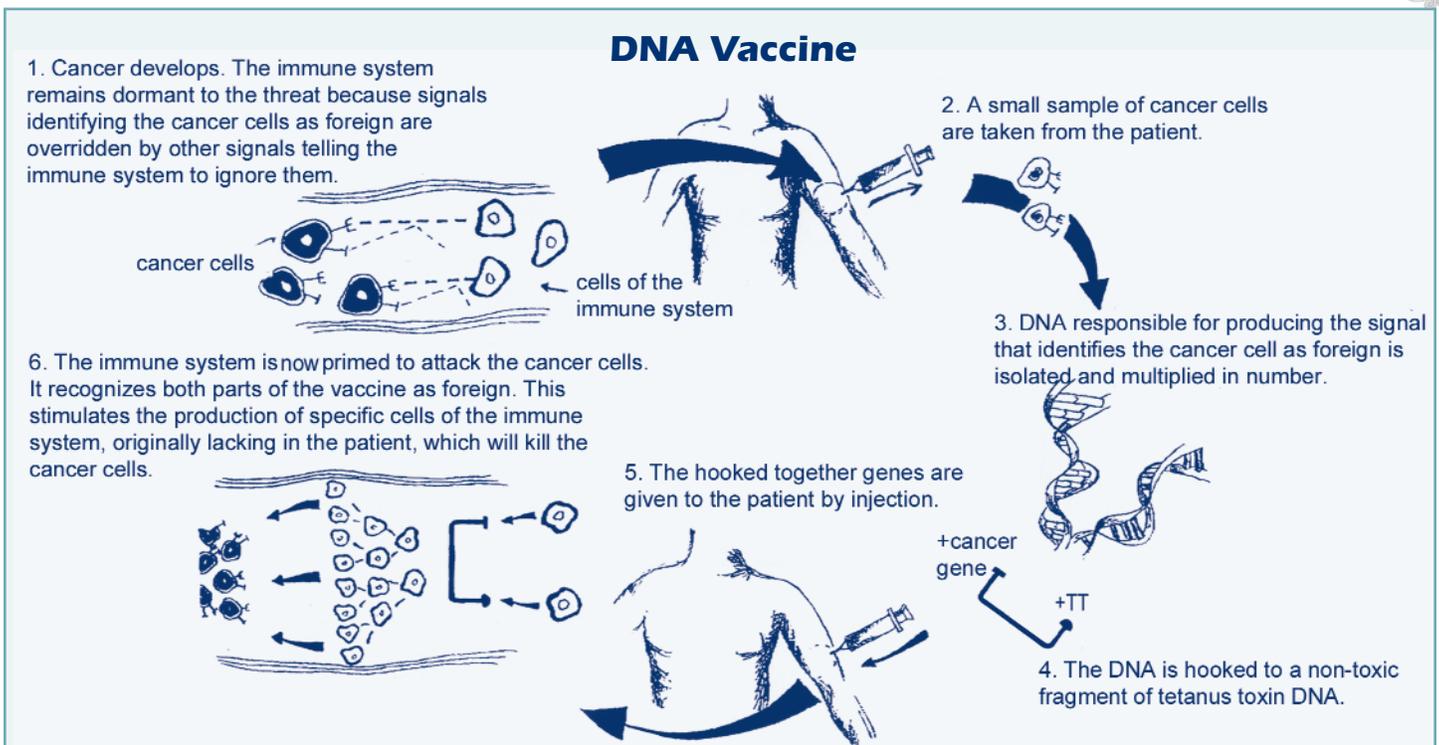
different group of T cells to "help" the anti-tumor response. Essentially, our tumor antigens are waking up the defeated immune system by pretending to be a pathogen.

*In addition to using this DNA vaccine to activate an immune response against residual cancer cells, in what other situations might this vaccine be used?*

One is to vaccinate a donor of an allogeneic transplant. This would mean that at the time of transplant, the transplant recipient would receive donor cells that already had a memory of the immune response against myeloma.

*How long do you estimate it will be before an effective DNA vaccine is available?*

A great deal will be learned from the current trial of DNA vaccines against lymphoma. In about 3 months we should know if we have induced immune responses in these patients with lymphoma. If we do, we shall apply immediately to the regulatory authorities to extend the trial to patients with myeloma. We estimate that we could be vaccinating patients with myeloma in about 7 to 8 months.



# You Need To Know

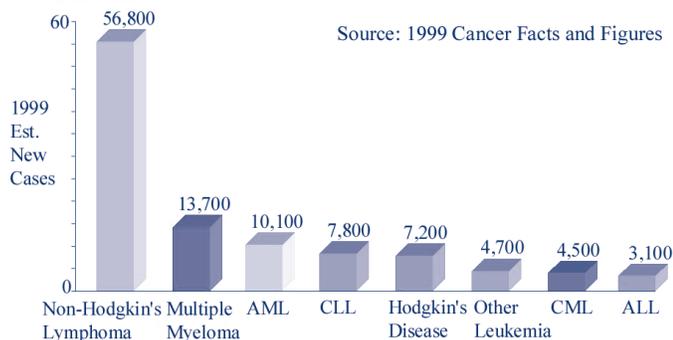
## Myeloma Statistics

### Recent statistics indicate:

- Multiple myeloma is the second most prevalent blood cancer.
- Approximately 50,000 Americans currently have multiple myeloma.
- 11,400 lives will be lost to multiple myeloma in 1999.
- Multiple myeloma is the 4th fastest growing cancer in terms of mortality.
- Multiple myeloma is one of the top ten leading causes of cancer death among African Americans.

Multiple Myeloma is the Second Most Prevalent Blood Cancer

Source: 1999 Cancer Facts and Figures



## 1999 Senior Research Awards **\$100,000 Senior Research Grant Applications now being accepted by MMRF**

The MMRF, in conjunction with the McCarty Cancer Foundation, awarded these grants last November and are once again accepting applications. The MMRF has distributed \$1 million in research grants to leading scientists throughout the world to support efforts in the most promising areas of cancer research. These grants allow researchers to implement biological, or clinical, research projects and carry them to fruition.

Senior research awards valued from \$75,000 to \$100,000 are awarded to researchers who have been working in the field of multiple myeloma for a minimum of five years.

Application deadline is May 31, 1999

The MMRF's 1999 Fellows Awards are valued at \$40,000 and are offered to researchers who are relatively new to the field of multiple myeloma. The deadline for Fellows Award applications is August 31, 1999.

For additional information, visit our website at:

[www.multiplemyeloma.org](http://www.multiplemyeloma.org)

## MMRF working with Center for Patient Advocacy

**T**he Health Care Financing Administration (HCFA), the federal agency that oversees Medicare, has proposed a significant change in the way Medicare reimburses healthcare providers. The proposed regulation will impact myeloma patients, since the disease often occurs in people over 50. The proposal encourages hospitals to use the least expensive chemotherapy options as opposed to the latest, most effective, options and discourages the use of supportive care drugs that help patients tolerate their treatments. The MMRF is working with the Center for Patient Advocacy in their fight against HCFA's proposed regulation and we have endorsed H.R. 1090, The Full Access to Cancer Treatment Act (FACT), which has been introduced in the U.S. House of Representatives by Congressman Gene Green (D-TX). We encourage everyone to write directly to Members of Congress. For sample letters and more information, please visit their website, or call Terre McFillen-Hall, at the Center for Patient Advocacy, at 703-748-0400, ext. 29. A Fact Sheet and sample letter are available at the Center's website, [www.patientadvocacy.org](http://www.patientadvocacy.org). The Legislative Advocacy Center's website allows you to send an e-mail message directly to Congress.



## Sweden Meeting

The VII<sup>th</sup> International Workshop on Multiple Myeloma will be held September 1-5, 1999, at the Stockholm City Conference Centre in Stockholm, Sweden. This meeting is designed for physicians and researchers. The program includes: the role of HHV8, high dose chemotherapy and stem cell transplantation, bisphosphonate therapy, interferon, tumor vaccination, etc. The MMRF will be attending, and will serve as an informational source for this event. All matters regarding registration, including hotel booking, social events and general information are handled by Congrex Sweden AB: Phone: +46 8 459 66 00 E-mail: [Myeloma@congrex.se](mailto:Myeloma@congrex.se)

# MYELOMA FOCUS

Newsletter of the Multiple Myeloma Research Foundation

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The Multiple Myeloma Research Foundation was created to fund cancer research for multiple myeloma to improve patient outcomes and to find a cure for the disease.

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The information herein is not intended to replace the services of trained health professional (or to be a substitute for medical advice.) You are advised to consult with your healthcare professional with regard to matters relating to your health, and in particular regarding matters which may require diagnosis or medical attention.

## Industry Partners News from Novartis: new clinical trials hotline

**Z**oledronate, a potent, third-generation bisphosphonate, is expected to be on the market in the United States and Europe in 2001. Bisphosphonates (bis-fos'fo-nâts) are a class of drugs that have been shown to treat and prevent bone complications in some diseases that involve bone. Bisphosphonates have demonstrated this in Paget's disease, osteoporosis, and in certain types of cancer. It is important to note that zoledronate is NOT a chemotherapy drug.

Currently, zoledronate is being evaluated in several ongoing studies. One study is evaluating zoledronate in patients with cancer-related bone lesions due to multiple myeloma or breast cancer. This is a Phase III clinical trial at a total of 139 sites across the country. The purpose of this randomized study is to determine if zoledronate, an investigational agent, is a useful therapy (safe and effective) for preventing bone complications in multiple myeloma and breast cancer patients. Participating patients will receive intravenous treatment every 3 to 4 weeks for 12 months with one of the following three treatments: either zoledronate 4 mg, zoledronate 8 mg, or Aredia® 90 mg. After the initial 12 months of this study, patients who want to continue bisphosphonate therapy will

be given Aredia 90 mg every 3 to 4 weeks for an additional 12 months. This study is expected to be completed by October 30, 2001.

You may be eligible to participate in this Phase III study if you:

- Are 18 years of age or older
- Have a diagnosis of Durie-Salmon Stage III multiple myeloma
- Have at least one bone lesion
- Are receiving anti-cancer therapy
- Have not received treatment with

bisphosphonates during the past year (*Exception: a single bisphosphonate dose is allowed, if at least 14 days before beginning the study*)

For more eligibility information about this trial, call the Novartis Oncology Clinical Trials Line, 1-800-340-6843. Someone will be available to take your call Monday through Friday from 9 am to 8 pm EST, or you can leave a message at other times. Remember, only the physician at the study site can determine if you are truly eligible to participate in this study.

To learn more about other ongoing clinical trials, contact the National Cancer Institute's Cancer Information Service at

1-800-4-CANCER (1-800-422-6237).

## Immune Therapy Symposium

**T**he Multiple Myeloma Research Foundation announces the 2<sup>nd</sup> Experts Roundtable on Immune Therapy along with the McCarty Cancer Foundation. The symposium will be co-chaired by Dr. Ken Anderson of the Dana Farber Institute, and Dr. Freda Stevenson of Southampton University in the United Kingdom. This annual symposium, held this year in conjunction with the VII International Workshop on Multiple Myeloma, brings together world-renowned leaders in myeloma and blood cancers.

The objective of the Symposium is to provide a physicians forum to share ideas and learning. Leaders in blood cancer and myeloma research will build a team approach to finding a cure. Symposium findings will be published in *Immunology Today*. The Symposium will take place August 31 and September 1, at the Grand Hotel, in Stockholm, Sweden.

# Honor a Friend and Support a Research Grant

**T**he MMRF invites you to honor someone special who has played a role in the battle against multiple myeloma - a patient, doctor, nurse, friend, or family member. Give the Acorn Pin as a gift, and ask them to wear it knowing they have been honored for their courage and kindness. Wear the pin yourself, to help build awareness of multiple myeloma and the MMRF. Every dollar you spend on the Acorn Pin supports a multiple myeloma research grant. MMRF has incorporated the acorn as its logo to symbolize that by funding early (seedling) research, we can have an everlasting (ever-green) impact on finding a cure.



## Acorn Pin Order Form

I have enclosed a check for \$ \_\_\_\_\_  
to purchase \_\_\_\_\_ Acorn Pin(s) at \$100.00 each.

Name \_\_\_\_\_

Address \_\_\_\_\_

Telephone \_\_\_\_\_

This beautiful, sterling silver pin, designed by Susan Barkann, of SueB

Designs, embodies the hope MMRF offers. The design of the pin is based on MMRF's award winning acorn logo, which was designed by Lauren Kaiser, at Time Inc. The pin comes in a floral box, with an inspirational note enclosed, which reads:

***"Thank you for being an inspiration to so many.  
Please wear this pin in good health knowing  
it is a symbol of love and hope"***

Enclose your check with this form in the attached envelope. You will receive your pin(s) within two weeks. Send your order today to be in time for Mothers Day!

Our special thanks go to Elizabeth Donald who spearheaded this wonderful program.

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