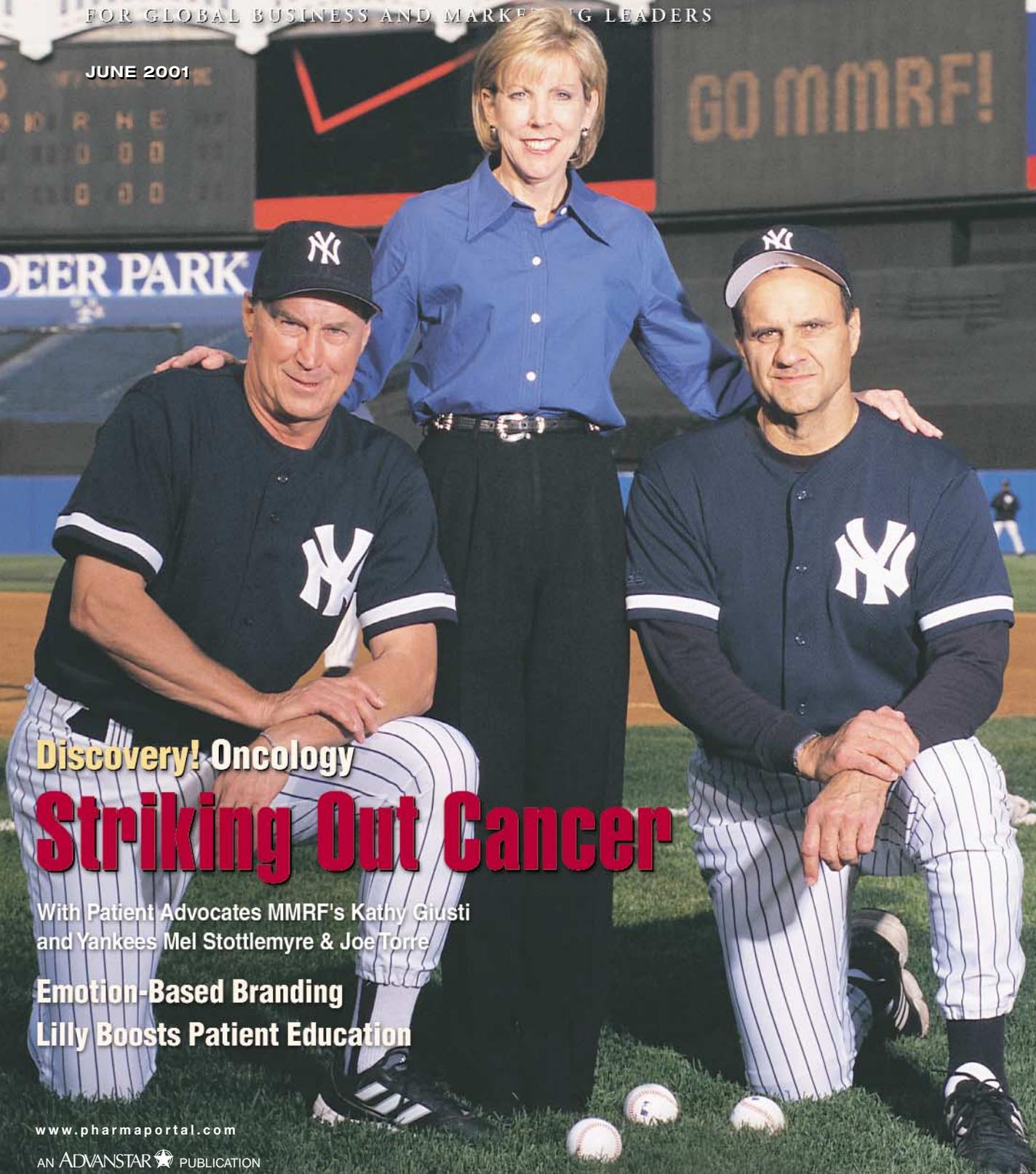


Pharmaceutical Executive

FOR GLOBAL BUSINESS AND MARKETING LEADERS

JUNE 2001



Discovery! Oncology

Striking Out Cancer

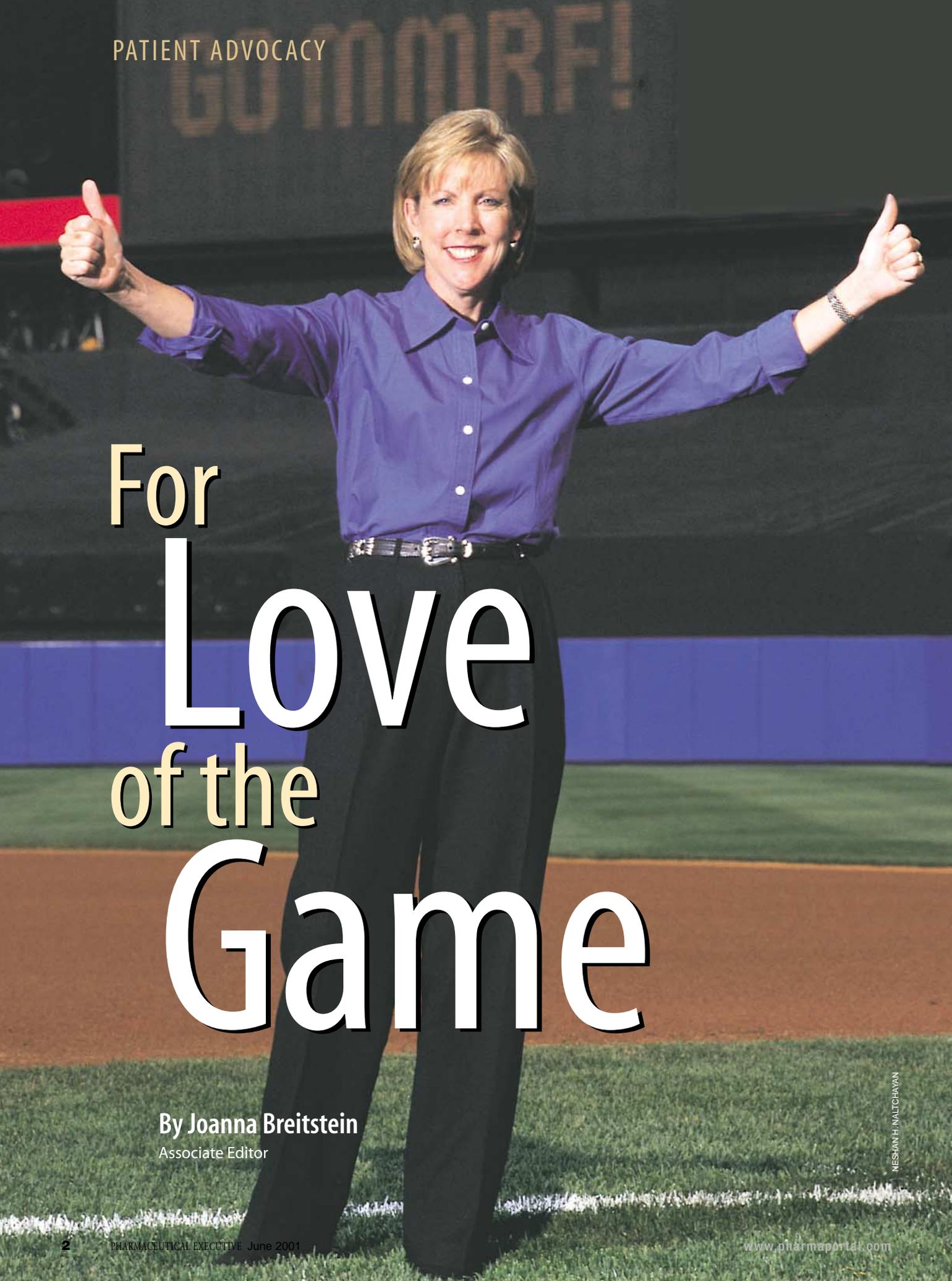
With Patient Advocates MMRF's Kathy Giusti
and Yankees Mel Stottlemyre & Joe Torre

Emotion-Based Branding

Lilly Boosts Patient Education

www.pharmaportal.com

AN ADVANSTAR PUBLICATION

A woman with short blonde hair, wearing a purple long-sleeved button-down shirt and black pants, stands on a baseball field. She is smiling broadly and giving a thumbs-up with both hands. The background shows a baseball field with a blue outfield fence and a dark sky. The word "GO HOME!" is faintly visible on the fence behind her.

For Love of the Game

By Joanna Breitstein
Associate Editor

NESHAN H. NALCHAYAN

Discovery!

Oncology



In 1996, when Kathy Giusti was diagnosed with multiple myeloma, a rare cancer of the bone marrow, there was no cure. Although some research institutions had begun working with the disease, it affected only 14,000 Americans each year, and lack of funding prevented any real progress.

Summoning the same determination and drive she used to climb the ladder in her pharmaceutical career, most recently with Searle, Giusti acted to save her own life, and in the process, the lives of other multiple myeloma patients. She gathered energy from the love of her husband and two children and quit her job. With the help of her twin sister, an attorney for Time Inc., she established the Multiple Myeloma Research Foundation (MMRF). Weaving a sophisticated web of public relations, partnerships, governmental advocacy, and scientific competence, MMRF gave voice to the myeloma patient population, elevated the disease to a national concern, and funneled \$8 million into research within three years.

But MMRF is only one of many advocacy groups working to beat cancer. Although each has its own focus and organizational style, together they are demonstrating just how much the new face of advocacy can accomplish.

Business Model

MMRF is run more like a Fortune 500 company than a foundation. It is defined by a mission, short- and long-term goals, a business plan for growth, a board of directors, and a scientific advisory board. The mix works. Under Giusti's stewardship, MMRF has exceeded fundraising expectations while remaining a model of efficiency—less than 5 percent of capital raised has been spent on administrative costs.

“Running the marketing department at the Gillette Company, Merck, and Searle, you have to report what your business plan is, how you will achieve your mission, and how you're going to staff and organize,” says Giusti. “The good advocacy organizations are starting to learn how to do that, and I think that's what really sets us apart.”

With the industry model as a strong foundation, Giusti's next challenge was to market MMRF to patients, other consumers, scientists, corporations, and government. She called on her background in pharmaceutical marketing, along with her perspective as a patient, to create the optimal marketing mix that would put multiple myeloma on the map.

Getting Attention

“When we initially tried to get press for multiple myeloma, no one had never heard of the disease,” says Giusti. “To raise the funding and to get people interested in the disease, you have to raise awareness.”

Although the media were already interested in the story of twin sisters creating a foundation to finance the search for a cure, Giusti gained additional attention in 1998 when the Healthcare Businesswomen's Association named her Woman of the Year and *Pharmaceutical Executive* put her on its cover. Since then, she has appeared on NBC's *Today Show*, Fox TV, *CBS This Morning*,

and CNBC, and has been featured in numerous print articles.

To add even more publicity to the fundraising equation, Giusti resorted to a tried-and-true approach—harnessing the power of celebrities. High-profile personalities, such as cancer survivors General Norman Schwartzkopf and St. Louis Cardinals baseball player Eric Davis, shared their experiences at MMRF's Friends for Life Fall Gala.

Davis was diagnosed with colorectal cancer during the baseball season of June 1997. Five weeks after having surgery, he returned to the field and hit a game-deciding home run in the playoffs. Fans showed their support with a five-minute standing ovation.

In addition to supporting MMRF's campaign, he has established the Eric Davis Foundation, a personal effort to reach out and inform people about colon cancer and the importance of getting colonoscopies. His foundation also provides support to patients and funds research to help accelerate the search for new screening techniques and treatments.

A highlight of the foundation's efforts is its campaign, Score Against Colon Cancer, for which Davis hits the road, meeting colon cancer patients and holding press conferences at hospitals where he talks about the disease. The campaign also brings awareness to the ballparks—with pregame ceremonies honoring colon cancer survivors, scoreboard messaging, and booths hosted by local hospitals distributing information about the disease.

Davis says his awareness efforts are important to all communities, but especially for African-Americans. “I thought colon cancer was mainly found in elderly white men,” says Davis. “But for me, I'm not elderly or white, so I have to get the message out to the African-American market because the majority of them don't know about colon cancer. After all, this is not a white disease, it's not a black disease—it's a deadly disease.”

Based on the success of the past two years—and the number of teams clamoring for events in its city—Score Against Colon Cancer will return to ballparks once again in June. The Eric Davis Foundation will use those events to bring attention to the new Medicare benefit, effective 1 July 2001, which covers colonoscopies. In three cities, the foundation will transport Medicare patients to the hospital, pay for a prescreening and consultation—which is not covered—and bring them back to get tested after the Medicare benefit is implemented.

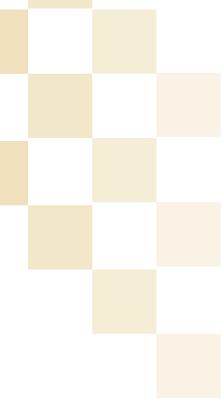
“To raise the funding and to get people interested in the disease, you have to raise awareness.”

Kathy Giusti



ERIC DAVIS FOUNDATION

Eric Davis honors colon cancer survivors in a pregame ceremony during the Score Against Colon Cancer campaign.



“We realized there was no information out there about early detection because most women were diagnosed with late-stage breast cancer.”

Karen Miller

Davis is not the only baseball personality to step forward. Recently, MMRF honored New York Yankees pitching coach Mel Stottlemyre, who described his battle with multiple myeloma at a fundraising gala and awareness award ceremony held at New York City’s upscale Cipriani restaurant. All-star attendees, including Yankees manager Joe Torre, bench coach Don Zimmer, and players Roger Clemens, Andy Pettitte, and Mariano Rivera, sports newscaster Bob Costas, former US congresswoman and vice-presidential candidate Geraldine Ferraro, and New York City Mayor Rudolph Giuliani, attracted national media to the event. Scores of pharmaceutical companies, healthcare agencies, politicians, New York socialites, and other advocacy volunteers also turned out to raise more than \$550,000 for multiple myeloma research.

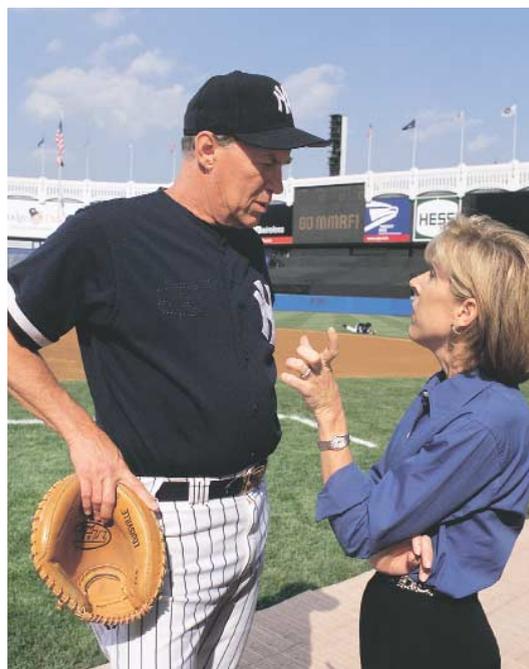
“I’m trying to do as much as I can for MMRF,” Stottlemyre told *PE* before accepting his award. “We don’t know a whole lot about this disease, and the only way we will know is to have research money to break the barriers and find answers.”

“Hopefully, no one else will join the ugly club I’m in now—the cancer club,” Stottlemyre said after Joe Torre presented him with MMRF’s public awareness award. “But now that I’m in, I’ll tell you this: Hopefully, I will stay around a long time—long enough to make a difference.”

Making the Model

Before MMRF, the Eric Davis Foundation, and a host of other advocacy groups, breast cancer advocates paved the way. “We, the breast cancer community, were taught to listen to our doctors and leave the rest to God,” says Lilly Tartikoff, co-creator of the National Women’s Cancer Research Alliance and co-founder of the National Colorectal Cancer Research Alliance. “It was the AIDS advocates and activists who taught us to find our voice, to take the fight into our own hands and to not be passive. In turn, breast cancer became a model for other cancer advocacy groups.”

Indeed, as breast cancer advocates looked on, AIDS patients were getting more money, more attention, and benefits from more effective re-



NESHAN H. NALCHAYAN

Mel Stottlemyre takes a break from coaching to discuss advances stemming from MMRF-funded research with the foundation’s Kathy Giusti .

search—all because of advocacy. So the breast cancer community adopted the AIDS ribbon, turned it pink, and used the women’s movement, which was receiving heightened media attention, as its vehicle.

“Years ago, women changed the treatment for breast cancer by pushing for alternatives to mastectomy,” says Diane Blum, president of Cancer-Care. “We now have lumpectomy. It was very important to educate physicians and healthcare professionals about that, but you really move things along when you go directly to the public.”

That philosophy became the mechanism of action for the Susan G. Komen Breast Cancer Foundation, established in 1982. It developed a formula that maximized efforts in funding breast cancer research and care:

- prime the market
- recruit consumers
- initiate advocacy
- become mainstream

Combating ignorance and social taboos, the

National Cancer Institute Research Dollars (in millions)

| | 1992 | 1993 | % | 1996 | % | 1998 | % | 2000 | % |
|-------------------|--------|--------|--------|--------|--------|--------|--------|--------|--------|
| | Actual | Actual | Change | Actual | Change | Actual | Change | Budget | Change |
| Breast | 145 | 268 | 85% | 318 | 19% | 349 | 10% | 408 | 17% |
| Colorectal | 69 | 83 | 20% | 98 | 18% | 121 | 23% | 133 | 10% |
| Lung | 76 | 106 | 39% | 119 | 12% | 140 | 17% | 150 | 8% |
| Prostate | 31 | 56 | 79% | 72 | 28% | 87 | 21% | 137 | 57% |

Komen Foundation concentrated on educating consumers about breast cancer and pointed to statistics they couldn't ignore: In one decade, more women died from breast cancer than there were Americans killed in all the wars of the 20th century combined.

Next, Komen established the Race for the Cure, a five-kilometer run held in cities across the United States to raise money for breast cancer research, education, screening, and treatment. The event was pivotal in making the disease real to the public and giving them a way to get involved in the battle against breast cancer.

The third step in the Komen formula called for government involvement. "Political advocacy works best when there is a groundswell of grass roots support," says Susan Braun, CEO and president of the foundation. "That has a lot to do with the Race for the Cure and other events like it, that have made breast cancer both visible and okay to talk about. People pay attention when we do political advocacy, because we have 70,000 active volunteers in 45 states. Policy makers and lawmakers realize that the constituency out there is vocal, visible, and relentless."

The last part of the Komen formula was to establish breast cancer as a mainstream concern, ensuring that its funding will continue to grow. Clearly successful, today the National Cancer Institute appropriates as many research dollars for breast cancer as it does for colorectal, lung, and prostate cancer combined (see "National Cancer Institute Research Dollars," page 52.)

As for the private sector, the relationship between breast cancer advocates and pharma continues to grow because they share many of the same goals. Educating women about mammography, for example, and driving them to get tested have topped breast cancer advocates' and industry's lists since 1985, with the inception of Breast Cancer Awareness Month.

"AstraZeneca helped start Breast Cancer Awareness Month, because 16 years ago, early detection was relatively new," says Karen Miller, director of ally development at the company. "We realized there was no information out there about early detection, because most women were diagnosed with late-stage breast cancer."

Advocates also help pharma companies develop and recruit for clinical trials to bring treatments to the market more quickly.

"Advocates were involved all along the way in the STAR [Study of Tamoxifen and Raloxifene] trial, including trial design and recruitment," says Miller. "The trial was for prevention, and the advocates at the oncology drugs advisory committee were the ones who recommended using the term 'risk reduction' rather than 'prevention.'"

Pharma has called on breast cancer advocates to help design materials for public relations campaigns. "Industry's reach into the medical profession to help educate patients and provide important materials to them is very, very, valuable," says Braun. "Paired together, we can do a whole lot to change the world."

Miller concurs, recalling how AstraZeneca authorized an ad agency to develop patient education materials for Nolvadex (tamoxifen) before getting patient input. "By the time the materials were created, we realized they contained wrong information," Miller says. "We learned our lesson. For Arimidex, we worked with the advocates."

Science in Motion

Patients and politics are only parts of the picture. Advocacy groups must also form alliances with researchers. One reason MMRF has come so far in such a short time is that its staff knows how to disseminate complex pharmacological information. The foundation also accelerates the search for cures by awarding millions of dollars in research grants each year.

In addition, MMRF encourages teamwork across "party lines" by holding quarterly roundtables to examine cutting-edge approaches to treatment. Notable leaders in cancer research such as Judah Folkman, MD, of Harvard Medical School Children's Hospital in Boston and leading scientists from the National Institutes of Health and major pharma companies attended the most recent roundtable, focusing on antiangiogenesis.

"Pharmaceutical companies are worried their competitors will come and learn, so they attend because they don't want to miss anything," says Giusti. "When they get there, they start to share knowledge and information, and that brings compounds to market more quickly. Dr. Folkman's input helped industry and academia look at antiangiogenesis in multiple myeloma in a different light."

Teaming Up

Patients can also benefit directly from advocacy-

"If Mel is being honored, I'm going to be here to support him," says Yankees pitcher Andy Pettitte, sitting beside teammate Roger Clemens at MMRF's recent fundraising gala.



industry alliances. MMRF, for instance, has immediate access to information about new treatments, approvals, and warnings, thereby circumventing the laborious multilayer legal process pharma companies must usually go through before they can post information on Web sites or in press releases. Using the expertise of its esteemed scientific advisory board, MMRF can confirm the effectiveness of new compounds and rapidly disseminate appropriate information to the myeloma community.

“We’ve identified ways to build those partnerships and to understand that pharma is the good guy,” says Giusti. “We’re very comfortable sitting side by side with them.”

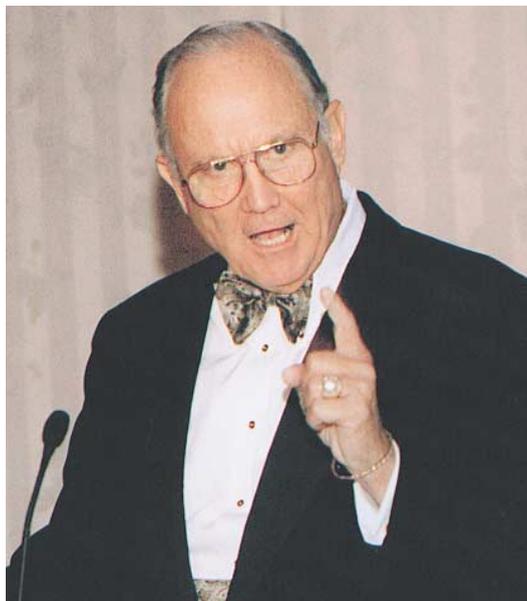
MMRF acts as a conduit between pharma and patients, flowing information about clinical trials to patients quickly through its sophisticated database. Harnessing available technology, the organization networks into homes, sending weekly e-mails, newsletters, and streaming broadcasts of medical meetings, symposia, and seminars. According to Giusti, MMRF has a database of thousands of e-mail addresses segmented by patient, clinician, researcher, patient’s family, or donor. The organization also spreads news of trials and treatments to patients through its Web site, helpline, CME programs for physicians, and patient seminars.

Giusti’s background in pharma helps her understand the importance of patients enrolling in well controlled trials to validate new therapies. Among others, the foundation has helped build awareness and speed recruitment for Millennium’s proteasome inhibitor, LDP341, the first in a new class of anticancer agents; Novartis’ Zometa (zoledronic), which treats multiple myeloma, breast, renal, and lung cancer; and Celgene’s ImiDs, synthetic derivatives of thalidomide with few side effects.

Giusti sits on the advisory panels of several pharmaceutical companies, including Celgene, whose Thalomid (thalidomide) is an effective therapy for multiple myeloma patients but not FDA-approved for that indication. On the boards, she provides perspective on patient issues, regulatory concerns, and marketing.

“Celgene is trying to handle its regulatory issues, because doctors can use the drug “off-label.” The point is, should somebody call us to participate in a hearing, we would try to help them as much as we could,” she explains.

Giusti is a watchdog for approved products undergoing trials for an indication in myeloma. When the *New England Journal of Medicine* published a study showing a 30 percent response rate



MMRF

“Every year we lose more people to cancer than I had under my entire command during the Gulf War,” says General Norman Schwartzkopf. “Every two days we lose more people to cancer than were killed at Pearl Harbor. We must declare war on cancer and stop this frightful waste of human lives.”

in refractory myeloma patients on thalidomide, MMRF sent the information to patients, throwing a lifeline to those for whom other therapies have failed.

“The industry is starting to see that we are the link for getting information about their products and clinical trials to the patient communities,” says Giusti. “They realize that link can really speed the drug’s approval process. That’s the driving factor for the pharma industry.”

Designated Hitters

Pharmaceutical alliances are only one part of the formula for change. Advocacy at the federal level is also necessary to ensure patients have access to new treatments. MMRF, working with a team of leading clinicians, has already succeeded in changing Medicare guidelines to cover experimental but highly effective stem-cell transplants for multiple myeloma patients.

But that was before Giusti discovered the strength in numbers. With the myeloma patient population hovering at around 50,000, MMRF decided to partner with other blood cancer advocacy organizations to strengthen their collective voice on Capitol Hill.

National Cancer Institute Director Richard Klausner, MD, agreed to include multiple

“Whenever a well-known person gets involved, it draws attention to that issue,” says Geraldine Ferraro, regarding her involvement with the blood cancer congressional hearing, scheduled for June.



MMRF

All Politics are Local



For decades, Sam Donaldson, a familiar and trusted anchor, brought world news into people's homes. Then a brush with cancer gave him a new perspective on his role as a public figure. He takes time from a busy schedule to share his views with *PE* readers.

Donaldson: As a member of the "cancer club," my specialty is melanoma. I had a tumor removed from my right groin in 1995, and that experience changed me from patient to advocate.

Tip O'Neill, late speaker of the house, said that all politics are local. For years, I have understood the need for medical

research, but certainly not with the passion that I do now that it has come home. I go almost anywhere to talk about the need for more money for cancer research. More than any other way, this great agent of ours, the US budget, is the way to channel money to peer-reviewed projects through NIH. And it makes sense. First of all, it will save lives—and that's the business we ought to be in. Second, it is cost-effective. If you want to fix a potential deficit in Medicare, you cure cancer.

If a foreign enemy invaded us and killed 500,000–600,000 Americans each year, we would pour trillions of dollars into the effort to push them back. So why do we devote so little of our resources, haggling over a few billion more for NIH?

I must tell you, I don't understand why people march and walk for money for their specific type of cancer. Why not get the groups together and see if they can work on not just finding interim therapies but curing this disease?

That idea started the National Dialogue on Cancer three years ago, chaired by George and Barbara Bush. The NDC gets all of the diverse groups dealing with cancer—the pharmaceutical industry, the healthcare industry, insurance, HMOs, scientists, patients, and survivors—together and tries to accelerate the search for the cure.

To increase general knowledge in the field, it sometimes takes six months to duplicate processes drug companies have discovered but will not give to NIH, even though they're not going to make any money from them. The pharmaceutical industry needs more protection, so it can share the work with other scientists sooner and use everybody's material to advance the cause. Excuse me if I talk about the birds and the bees, but cross-pollenization will get us much farther down the road to curing cancer.

myeloma in a blood cancer progress review group (PRG), a multidisciplinary panel of prominent scientists, clinicians, industry representatives, and advocates who set the national blood cancer research agenda for the next five to ten years.

"The PRG was the first time that we were in constant meetings together," Giusti recalls of the first collaborations with the Cure for Lymphoma Foundation and the Leukemia and Lymphoma Society. "We started realizing that we have so much in common, and, with so many great things happening with leukemia, PRG is almost a role model for how to find cures faster for lymphoma and myeloma. We decided that so many novel ideas were covered in its business plan that we wanted to make sure it didn't sit in a filing cabinet somewhere."

So the three groups started talking to people on Capitol Hill, hoping to schedule a congressional hearing to address the need for more funding. Giusti's efforts caught the attention of Geraldine Ferraro, who helped the groups put it in motion.

dine Ferraro, who helped the groups put it in motion.

"I called Senator Kay Bailey Hutchison, whose brother has multiple myeloma, and asked if she could speak to Senator Specter about a hearing," says Ferraro. "A date was set for 21 June 2001."

It will be the first time all blood cancer groups present a unified front in Washington, DC. Giusti is excited because she thinks cohesive approaches are the way to make a big difference.

Together, the groups hope to educate Congress, the media, and the public about barriers to and opportunities for research, increase policy makers' awareness of hematologic cancers, and secure additional funding from the Senate for research leading to cures for blood cancers.

"We want government to help, and we want industry to help, but we want to do our fair share, too," Giusti reflects. "Working together, we will find a cure much more quickly." ■

"I called Senator Kay Bailey Hutchison, whose brother has multiple myeloma, and asked if she could speak to Senator Specter about a hearing. A date was set for 21 June 2001."

Geraldine Ferraro

Information about multiple myeloma

MULTIPLE
MYELOMA
RESEARCH
FOUNDATION



What is multiple myeloma?

Multiple myeloma is a cancer of the plasma cells, important cells of the immune system that produce and release antibodies (immunoglobulins) to help fight infection. Malignant plasma cells produce an abnormal immunoglobulin making myeloma patients susceptible to infection.

What causes multiple myeloma?

While the specific cause of multiple myeloma has not been identified, possible associations include a decline in the immune system, genetic factors, exposure to certain chemicals, radiation and viruses.

What are the common symptoms of myeloma?

Pain in the lower back or ribs, which is the result of accumulations of plasma cells that cause tiny fractures in the bones.

Unusual tiredness due to anemia.

Frequent recurrent infections such as bacterial pneumonia, urinary tract infections or shingles.

Hypercalcemia and kidney failure can also be seen in myeloma patients.

How common is multiple myeloma?

Multiple myeloma, the second most common blood cancer, represents 1% of all cancers and 2% of all cancer deaths.

This year, 14,400 Americans will be diagnosed with multiple myeloma and 11,200 Americans will die of the disease.

The incidence of multiple myeloma is higher in African Americans than it is in whites (9.5 versus 4.1 per 100,000). Multiple myeloma is a top ten cancer killer of African Americans.

Multiple myeloma is fourth fastest growing cancer in terms of mortality.

What are the current treatments for myeloma?

Multiple myeloma is considered an incurable cancer today. The following approaches are used to improve the patients' quality of life by controlling the complications of the disease: chemotherapy with melphalan and prednisone, high-dose chemotherapy followed by stem cell transplant and thalidomide.

Multiple
myeloma is a
cancer of the
plasma cells....



Information about MMRF

MMRF is a
non-profit
organization
driven by a
single purpose
—to accelerate
the search for a
cure...

What is the Multiple Myeloma Research Foundation (MMRF)?

The MMRF is a non-profit organization driven by a single purpose – to accelerate the search for a cure for multiple myeloma.

Incorporated in 1998, The MMRF remains dedicated to improving therapeutic options for people with multiple myeloma by:

- ***Funding the most promising myeloma research:***

The MMRF is the world's leading private funder of myeloma research offering Senior Research Awards of \$100,000, Fellows Research Awards of \$40,000 and Program Grant of \$1.5 million

- ***Building collaborations among researchers and industry:***

The MMRF conducts Expert Research Roundtables – worldwide symposia serving as think tanks for top myeloma specialists to discuss cutting-edge science topics such as cell signaling, microenvironment, and microarray technology

- ***Providing information to patients and family members:***

The MMRF provides the myeloma community with the latest research information fast and free of charge via its website, webcasts, email updates, newsletter, teleconferences, and educational symposia

- ***Raising awareness of multiple myeloma:***

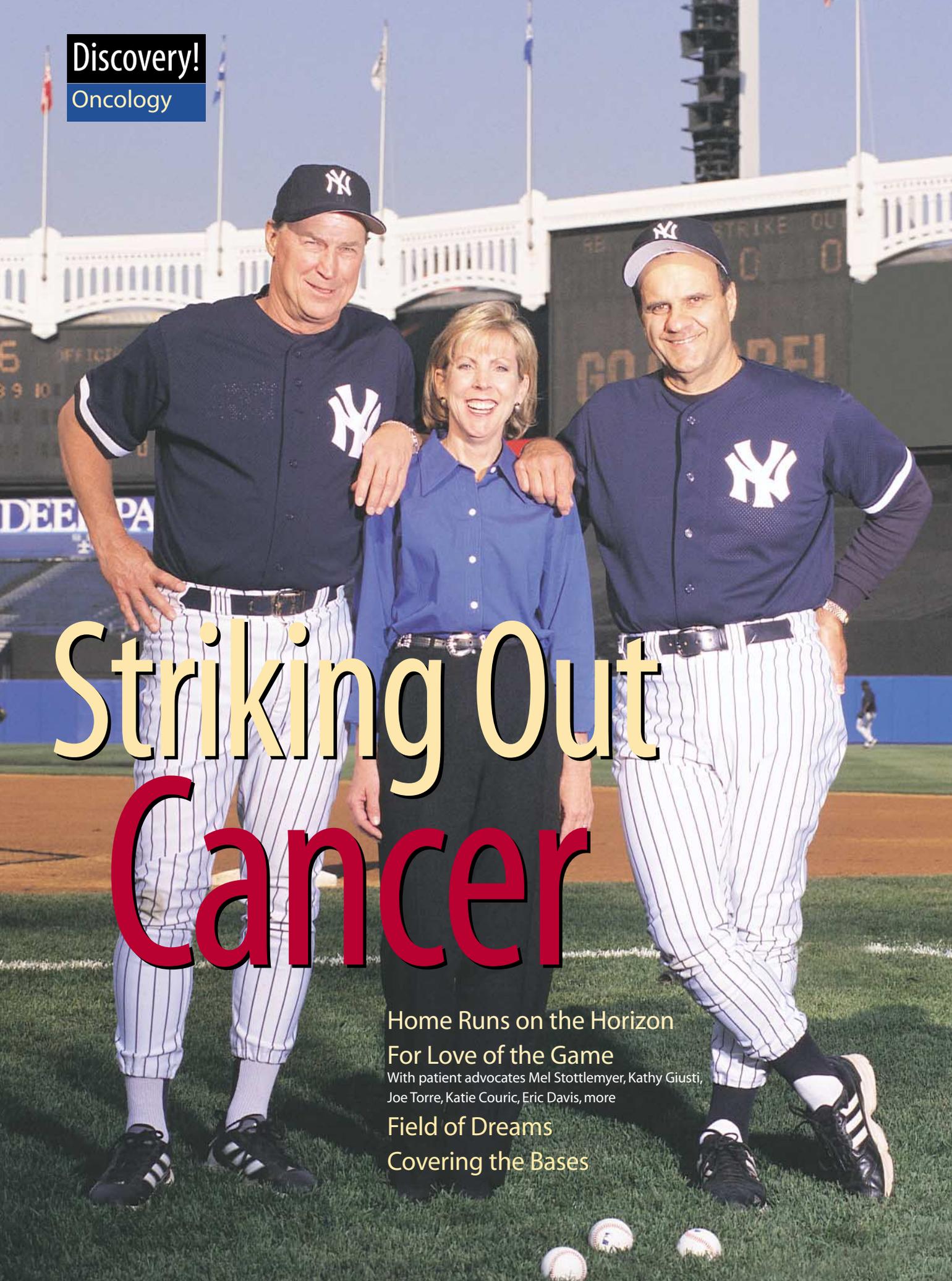
The MMRF has reached millions of Americans with feature segments on NBC Today Show, CNBC, CNN/SI, CBS This Morning, Fox News and Inside Edition

- ***Advocating optimal patient care:***

The MMRF helped spearhead the first-ever congressional hearing on blood cancers in June 2001

Discovery!

Oncology

A photograph of three people standing on a baseball field. On the left and right are two men dressed as New York Yankees players, wearing dark blue jerseys with the Yankees logo and white pinstriped pants. In the center is a woman wearing a blue button-down shirt and a black skirt. They are all smiling and have their arms around each other. The background shows a baseball stadium with a scoreboard and a white bridge structure.

Striking Out Cancer

Home Runs on the Horizon

For Love of the Game

With patient advocates Mel Stottlemyer, Kathy Giusti,
Joe Torre, Katie Couric, Eric Davis, more

Field of Dreams

Covering the Bases

The MMRF
provides the
myeloma
community
with the latest
research
information...



MMRF

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