

FamilyCircle

The *Advocacy* Advantage

By Jo Cavallo

Why Some Patients Get Better Care

When my brother, Dom, 59, called to tell me that he had been diagnosed with a rare—and often fatal—blood cancer called multiple myeloma, which affects the bone marrow and compromises the immune system, his words hit me like a body blow, momentarily taking my breath away. I immediately went into denial.

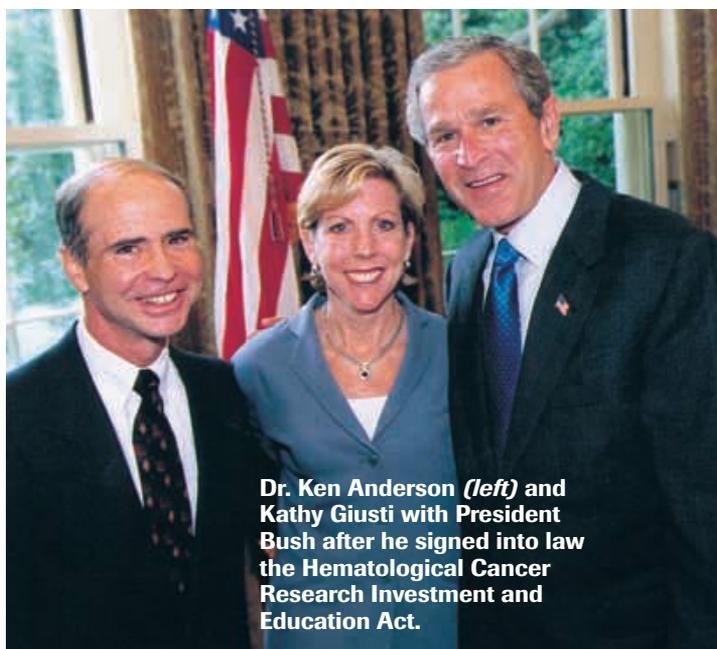
“There must be some mistake,” I said. “There’s no history of cancer in our family.” But the test result from a bone-marrow biopsy was positive, and his doctor was urging him to check into a hospital right away to begin standard treatment for the disease: massive doses of chemotherapy, followed by a bone-marrow transplant and months-long hospitalization. Although the cancer was in an advanced—but fortunately, slow-growing—stage, and since even a successful transplant is no guarantee against a relapse, Dom wanted to wait and learn everything he could about the disease before making a decision.

Even though my brother is nearly four years older than I am, I’ve always been fiercely protective of him. Brilliant and

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generous, Dom has a quick wit that’s impossible to resist and we’ve always been pals. He was my partner in making difficult end-of-life medical decisions when our parents became ill, and now, having lost my mother just the month before Dom’s diagnosis, I was determined that I wasn’t going to lose him too.

Partners once again in a new health crisis, we immediately turned to the Internet looking for information about his disease. The news was terrifyingly grim: One person in 100,000 is diagnosed each year with multiple myeloma, 14,000 die, the life expectancy with treatment is three to five years, there’s no known cause or cure. Yet among the dire statistics was also hopeful mention of new remedies on the horizon. The most promising was thalidomide, a drug banned in the 1960s after it caused severe birth defects in babies of women in Europe and Canada who had taken the



Dr. Ken Anderson (left) and Kathy Giusti with President Bush after he signed into law the Hematological Cancer Research Investment and Education Act.

drug to prevent morning sickness. Although never approved by the U.S. Food and Drug Administration for that purpose, thalidomide was okayed as a treatment for leprosy and is now being used to treat myeloma. One of the ways the drug works is by preventing cancer cells from growing by cutting off their blood supply, making it impossible for the renegade cells to take hold in the bone. (See “What’s Multiple Myeloma?” page 2.)

“Right away I started to read about myeloma and I found out about thalidomide,” says Dom. “And I thought that if

“I equate cancer **survivorship** with cancer advocacy.”

What's Multiple Myeloma?

Multiple myeloma is a cancer of the blood in which plasma cells reproduce uncontrollably in the bone marrow, releasing growth factors that spur development of new blood vessels. Tumors form and eventually begin to attack the hard outer part of the bone, creating soft spots or lesions. The

spread of these lesions—the *multiple* in multiple myeloma—weakens bones, causing them to fracture and break. The second most common blood cancer, myeloma was once considered a disease of the elderly, but recent statistics show a trend of rising incidence and younger

age at onset. The disease is twice as common in men as in women and is one of the 10 leading causes of cancer death among African Americans. For more information, contact the Multiple Myeloma Research Foundation at 203-972-1250 or visit its Web site at www.multiplemyeloma.org.

that was appropriate treatment for me, if it could work for me, it would be a far less drastic therapy than the standard treatment for myeloma, which is a bone marrow transplant. And if that could be avoided, that's what I wanted to do because the conventional treatment seemed awfully drastic and potentially life threatening."

Over the next few weeks my brother saw four oncologists specializing in multiple myeloma, the first three of whom suggested a bone marrow transplant. "There was nothing wrong with what they were recommending," he says. "Indeed, even the fourth doctor said that if there is such a thing as a cure, that's the most likely approach. But he also said, 'Why not try something that is less drastic, less painful, less altering in terms of your life, and see if that works first? And if it doesn't, then we can go to these other steps.' So that's what I decided to do."

A year after taking daily doses of thalidomide along with an experimental regimen that had initially included a potent steroid called dexamethasone, and monthly infusions of Aredia, a bone-strengthening medication, Dom appears stable. But our optimism is tempered by the knowledge that this disease can be wildly unpredictable and that while thalidomide has proven to be miraculously effective for him—only a third of advanced myeloma patients benefit from the drug alone—the side effects are becoming worrisome.

A sedative, thalidomide can leave Dom feeling fatigued, but by far the most troubling side effect is the onset of neuropathy, a sensation of tingling and numbness in his hands and feet caused

by progressive and permanent nerve degeneration. Still, over the course of his treatment he has maintained a vigorous teaching schedule at a university near his home on Long Island and leads an unrestricted lifestyle, something that would have been impossible with conventional treatment.

Racing for a Cure

To stay current on new therapies being tested for multiple myeloma, we signed up to get SmartBrief, a free, weekly online newsletter published by the Multiple Myeloma Research Foundation (www.multiplemyeloma.org). When I read in the spring of 2002 that the MMRF was looking for people to go to Washington, D.C., to participate in Blood Cancer Coalition Advocacy Days, I immediately volunteered. Besides meetings with members of Congress to ask for increased funding for blood cancer research and patient education, the agenda included presentations by leading researchers in multiple myeloma, leukemia and lymphoma on cutting-edge treatments being tested (one of which, Velcade, was recently approved by the FDA). At a chance encounter with one of those researchers, I learned that an actual cure for blood cancers is predicted to be less than five years away.

But what was immediately reassuring to me was meeting myeloma survivors who had been in remission for 8, 10 and even 15 years, and talking with Kathy Giusti, 45, president and cofounder of the MMRF, who was diagnosed with multiple myeloma eight years ago. (See "Women Who Make a Difference" in *FC's* May 13, 2003, issue.) "If anything changes with

your brother's condition, contact me right away," Giusti told me, "and we'll find him help." It was also comforting to hear Ken Anderson, M.D., director of the Jerome Lipper Multiple Myeloma Center at the Dana Farber Cancer Institute in Boston, tell myeloma patients to contact him "if you have any complications or need advice."

Making a Difference

So how important is being a well-informed health consumer in the outcome of your illness? "There's no question that it adds demonstrably to someone's quality of life," says Ellen Stovall, 57, president of the National Coalition for Cancer Survivorship (www.canceradvocacy.org) in Silver Spring, Maryland. "I equate cancer survivorship with cancer advocacy. The notion of what survivorship means is really what advocacy is and that is being an informed, educated, knowledgeable person about whatever life circumstance you find yourself in that's challenging. And cancer is a metaphor for how we can do that well, because it presents a crisis in somebody's life—family members, friends and coworkers, everybody is frightened about this disease."

Those words express more than just Stovall's professional opinion. In 1971, a month after giving birth to her son, Stovall was diagnosed with Stage 4 Hodgkin's lymphoma, a cancer of the lymph system, and was given a life expectancy of only two years. Ineligible for a promising, but at the time still experimental, chemotherapy drug because of her weakened condition, Stovall was treated with high-dose radiation to shrink an inoperable tumor sandwiched between her lungs and attached to her heart. "The radiation was meant to buy me some time," says Stovall, "but the doctors really didn't expect me to live."

Scared, Stovall felt a tremendous need for emotional support, but didn't want her family to know how frightened she was. "I wanted to talk to somebody outside my family because I wanted to be able to articulate my fears. I had a new baby and I wanted to talk to other young adults with cancer," she says. But 32 years ago cancer support groups didn't exist, so Stovall started her own. "I wasn't thinking of doing it for other people, it was purely selfish, but

Surviving a **serious** illness sometimes takes a team effort.

organizing a support group ended up helping a lot of other people. I realized then that my experience of having cancer really had something to contribute to other people.”

Surprisingly, the radiation treatment put Stovall’s cancer in remission, and she spent the next 12 years volunteering for the American Cancer Society, going door-to-door raising money and educating people about the disease. “Cancer was so stigmatizing thirty years ago,” says Stovall. “I can still remember the cancer ward at the end of the hallway in Georgetown University Hospital. It was totally separate from the rest of the building.” A recurrence of the disease in 1984 made Stovall even more determined to help other patients cope with cancer.

“I wanted to live so badly that I thought, *If I survive this, I’m going to devote the rest of my life to doing something about this disease,*” says Stovall. Today, once again cancer free, Stovall fulfills that promise every day as head of the National Coalition for Cancer Survivorship, the only patient-led cancer advocacy organization in the country.

Knowledge /s Empowerment

When Susan Scherr, 61, was diagnosed with breast cancer 26 years ago, she desperately tried to be proactive in her treatment plan but was frustrated at every turn. Told that she had no option but to have her cancerous left breast removed, Scherr searched for a less invasive treatment. She found information about a then little-known procedure called lumpectomy, in which only the tumor and underarm lymph nodes are removed, leaving the rest of the breast intact.

“Today I would be the perfect candidate for a lumpectomy, but back then I couldn’t find a doctor to perform it,” says Scherr, so she went ahead with the mastectomy. “Everything seemed so cut-and-dried even though I was doing everything possible to find information and be proactive.”

Married with two young children, Scherr was anxious to get on with her life and put her illness behind her. As the fifth and then the tenth anniversaries of her diagnosis passed without incident, Scherr finally started to relax. “I was told if I made it to ten years without recurrence, I would be considered cured. I believed it, and in the eleventh year I thought now life resumes,” says Scherr. But in 1988 she was again diagnosed with cancer, this time a rare and aggressive form of uterine sarcoma, and was given six months to two years to live.

After seeking a second opinion with the aid of her husband, Leslie, Scherr underwent the third of three grueling surgeries plus radiation and chemotherapy treatments. Convinced that she was going to die, she decided to quit her high-powered job as vice president of a national personnel firm to spend more time with her family. But as Scherr passed the critical two-year mark with her cancer still in remission, she started to feel cautiously optimistic about her future. “One part of me is always waiting for the other shoe to drop, but it’s far in the back of my mind,” says Scherr. She began attending support group meetings of the National Coalition for Cancer Survivorship near her home in Potomac, Maryland, and, like Ellen Stovall, eventually went to work for the

organization. She recently retired as director of program development. Her job was to help ensure that nearly 9 million cancer patients and their family members get the information and support they are looking for.

A Team Effort

According to Dr. Ken Anderson, being proactive in your own health care can also help raise awareness of specific diseases—especially rare diseases—on the national level. “I always talk about the team concept and partnership among the patient, caregivers, researchers, people at the National Institutes of Health and the FDA,” he says. “Only when all of those groups are pulling toward the same goal do we actually make meaningful progress that’s going to impact the lives of patients.”

Representing my brother Dom at the 2002 Blood Cancer Coalition Advocacy Days in Washington, I saw just how effective that team effort could be. The work of the 300 advocates on that occasion resulted in the House passing the Hematological Cancer Research Investment and Education Act, which President Bush signed into law.

“I know that people can become very cynical about what they can and cannot do and how coming to Washington does or doesn’t make a difference,” says Stovall. “I can say unequivocally that when advocates, patients and family members show up in Congress, members pay attention. Lobbying by advocates can change public policy as quickly as any insurance lobby. We should not minimize its importance for a second.”

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