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The Advocate
Sunday, July 11, 2004



Kathy Giusti of New Canaan is president and founder of the Multiple Myeloma Research Foundation. Giusti was diagnosed with the rare blood cancer in 1996 and established the organization with her twin sister in 1998.

Kathleen O'Rourke/
Staff Photo

On the trail of a cure

Cancer patient appointed to national advisory board

By Suzanne Sorrentino

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NEW CANAAN – After Kathy Giusti got her cancer diagnosis in 1996, she started doing the math. The doctors gave her three years to live and her daughter, Nicole, was 1 1/2. She might never see her only child start kindergarten.

At the time, Giusti dreamed that she'd make it to Nicole's fifth birthday, and that she'd be able to have another baby.

She never thought that eight years later she would be running the biggest private funder of research on multiple myeloma, a rare form of blood cancer she lives with, and that her efforts would bring drugs to the market that help extend the

lives of people with the disease.

"I never really meant to take all this on," Giusti says while sitting at her desk in the New Canaan offices of the Multiple Myeloma Research Foundation that she founded with her twin sister, Karen Andrews of Greenwich, in 1998.

Last month, Giusti received a presidential appointment to the National Cancer Advisory Board, where she hopes to use her experience as both a cancer patient and the leader of a research foundation to ensure that funding keeps up with new research on cancer treatments and patients' needs.

The NCAB advises the secretary of the Department of Health and

Human Services and the director of the National Cancer Institute on cancer research, training and information dissemination.

"I view this as a real honor and a huge opportunity to help a broad and diverse group of patients," Giusti says. She sees a main part of her role as ensuring that government funding keeps pace with new trends in research, especially research galvanized by the completion of the Human Genome Project. She also wants to ensure that research addresses the emotional needs of people living with cancer and their families.

After Giusti's diagnosis, she and her husband, Paul, decided to try to have another child. Their son,

David, was born in May 1997, and the following month the family moved from Chicago to New Canaan, where they would be closer to her sister, and her husband's family in Stamford.

"I needed my sister to help raise my children, because I knew I was going to die," Giusti says. "I knew there would be a lot more family support."

Giusti and her sister teamed up that October to put on a fund-raiser for multiple myeloma research. Giusti, with an undergraduate degree in biology and a business degree from Harvard, had worked in marketing for several major pharmaceutical companies, including Merck, Gillette and



Photo/ Marc S. Levine/ New York Mets

Giusti joins New York Mets hitting coach Don Baylor, left, new York Yankees pitching coach Mel Stottlemyre, center, and Mets manager Art Howe to throw out the first pitch at a Subway Series game last weekend at Shea Stadium. Three companies donated \$1,000 for each home run hit during the series.

Searle. Her sister, a lawyer, worked for Time Inc. and had access to people experienced in event planning, Giusti says.

The fund-raiser was successful and in 1998, the sisters established the foundation.

The foundation now partners with pharmaceutical companies to fund research on multiple myeloma.

While multiple myeloma is the second most common blood cancer, it represents only about 1 percent of all cancers. As an "orphan cancer," it is one that pharmaceutical companies are less likely to focus their research dollars on, Giusti says.

About 45,000 people in the United States have multiple myeloma, which is incurable, and an estimated 14,600 new cases are diagnosed each year, according to the myeloma foundation's Web site, www.multiplemyeloma.org.

Through what Giusti calls "risk sharing," she convinces pharmaceutical companies to partner with the foundation to do the research. The foundation has raised around \$27 million for such efforts.

Last year, the foundation helped bring to market the drug Velcade, which can help extend the lives of multiple myeloma patients. Revlimid, another drug the foundation helped develop to help prolong life, is expected to come out next year, Giusti says.

In addition to funding research, the myeloma foundation works to raise awareness about the disease and provide a network for patients and their families.

During last weekend's Subway Series at Shea Stadium, for example, Giusti teamed up with N.Y. Mets hitting coach Don Baylor and Yankees pitching coach Mel Stottlemyre, who both have multiple myeloma, to throw out the first pitch. The stunt was more to raise awareness than funds, Giusti says. But three companies - UBS, Celgene and Novartis - each anted up \$1,000 for the foundation for each home run scored during the series.

The foundation also maintains a database of 90,000 people affected by multiple myeloma who can use the foundation's Web site to learn about the disease and to find out

what research trials they might be able to participate in. The site gets about 100,000 hits per quarter, Giusti says.

Giusti says she gets satisfaction from the knowledge that her work helps people. But, it also forces her to confront her own illness daily.

"You never get to leave cancer," Giusti says. "With a database of 90,000, I lose a friend every day. ... I go to way too many funerals." One of the hardest things she's had to do so far, though, is tell her children that she has cancer.

Although they knew what multiple myeloma was since they heard their mother talking about it on the telephone, Giusti says only last year was she able to sit them down and tell them that this disease was cancer. Nicole, 8 at the time, understood what that meant.

"When it connected, she had this devastating look on her face. I told her it was going to be OK," Giusti says. "I couldn't do that before last year."

Giusti says the FDA approvals of the new drugs have given her tremendous hope for the future.

Currently, Giusti is considered a

"smoldering patient," meaning that her cancer cells are growing very slowly. She is monitored every 10 weeks at Stamford Hospital, and so far, her own immune system seems to be holding the disease in check. If that changes, Giusti would likely need a stem cell transplant from her sister and might begin taking one of the drugs she has helped take to market.

She says now, as she begins her six-year term on the national cancer board: "I have a long-term perspective. ... I believe I'm going to be here for a while."