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Working Against the Clock for a Cure

By JANE GORDON

ONE day after Kathy Giusti testified with Geraldine A. Ferraro at a congressional hearing on blood cancers late last month, she was zipping up the Merritt Parkway on her way home to New Canaan, cell phone to ear, catching up on her kids, the media, a cure for multiple myeloma.

She has no time to spare. She discovered she had the disease Jan. 12, 1996 — cancer sufferers always seem to remember their date — and drove immediately to a bookstore. She pulled Harrison's Principles of Internal Medicine off the shelf, searching for her cancer in its pages. Her best-case prognosis: three to four years. Her worst: three months.

She learned quickly that little research was being done for multiple myeloma, a blood cancer that erodes the bones. A pharmaceutical executive for Searle at the time, she had a degree from the Harvard Business School and extensive experience in marketing. With the help of her identical twin, Karen Andrews, a lawyer with Time Inc., she founded the Multiple Myeloma Research Foundation, which in just four years has grown to become one of the primary nongovernmental investors in myeloma research.

Perhaps more important, though, the drive has rallied the pharmaceutical industry, myeloma experts, celebrities and legislators to work together in hopes of a cure. Senator Kay Bailey Hutchison, a Republican of Texas, whose brother Alan has the disease, helped arrange the congressional hearings nine days ago, the culmination of four years of intense work for the foundation.

Ms. Ferraro, the former congresswoman, announced late last month that she has multiple myeloma, although Mrs. Giusti had known about her friend's illness for two years. The two met after Ms. Ferraro's daughter, Donna Zaccaro, was searching for information on the Internet,

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discovered the foundation's site and contacted Mrs. Giusti.

Mrs. Giusti, 42, is part of a maelstrom of activity on myeloma. But in 1997, she was alone in her house in New Canaan, new to the neighborhood and trying to figure out how to raise money for research so she could live to see her children graduate from preschool.

"I remember her sitting in my office and she said, 'There's no research going on,'" said Dr. Philip Greipp, a hematologist and myeloma researcher at the Mayo Clinic in Rochester, Minn., where Mrs. Giusti had gone for yet another opinion, far beyond the second. "So she went out, and she did something about it."

She had moved the family to Connecticut from Chicago to be near her sister when she first learned of her illness and had few friends in the area. Mrs. Andrews, who lives in Greenwich, called everyone she knew, and they packed

their first fund-raiser at the Greenwich Hyatt ballroom to raise half a million dollars.

The foundation's business plan, which reads more like that of a venture capital firm than a typical charitable organization, impressed other donors.

One sent a \$500,000 check through the mail. "I've read your financials," the donor told Mrs. Giusti. "I just know you're going to make a difference."

Mrs. Giusti, ill but ever the executive, remembered saying to herself: "This year I hit half a million. Next year I've got to hit a million."

"I knew I needed to do more," she said. "Good or bad, that is my personality. I never stop."

Her persona is evident at first glimpse. She cried when she told her sister she was sick, but otherwise the tears have been held in check. Her house is immaculately kept, her foundation is run like the sales floor at Nordstrom's — you want it, we'll get it.

When she was first diagnosed, she tried to move more quickly than her cancer. She wanted another child, a sibling for her daughter Nicole, 6, and she argued with doctors who opposed a pregnancy. As is typical for her, she prevailed, and in May, 1997 she and her husband, Paul, had David, who is now 4. "I find out I'm going to die, and I'm not going to have a sibling for my daughter, and my heart is broken," she said. "I wanted another baby. And I figured, if that's the last thing I do, that's O.K."

But her to-do list lengthened. She pushed harder to raise money for what researchers call "an orphan cancer," one of many that account for small numbers — in this case 1 percent — of the total cancer population. But the disease has a high mortality rate: More than 14,000 new cases are diagnosed annually, and 11,200 people with the disease are expected to die this year.

Her efforts have paid off. This year, her neophyte foundation will raise about \$4 million. The federal government's budget for myeloma research in 2001, by comparison, is about \$20 million. The Leukemia and Lymphoma Society commits about \$5 million annually to myeloma; the American Cancer Society about \$2 million each year.

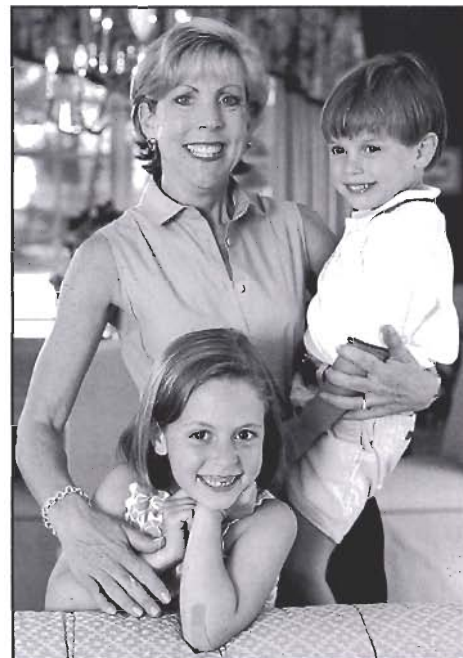
"The squeaky wheel gets the grease," Mrs. Giusti likes to say, and she persuaded influential people to squeak loudly enough for the government to hear. During the congressional hearings on June 21, Richard Klausner, the head of the National Cancer Institute, asked if he would be focusing more attention on blood cancer research, answered, "Absolutely."

For myeloma researchers who have been trudging along with little money, the answer was greeted with what passes for glee in scientific circles.

"I have for 20 years tried to develop new treatments for myeloma, to move them from the bench to the bedside," said Dr. Ken Anderson, a professor at Harvard Medical School and a hematologist/oncologist at the Dana Farber Cancer Institute in Boston. He is Ms. Ferraro's doctor and one of Mrs. Giusti's. "Now, the opportunities are unprecedented."

Blood-cancer research has benefited the treatment of all cancers, Dr. Anderson said, because tumor cells are easily accessible through the blood. "We bring them into the lab to study how they grow and survive and resist new agents," he said. "The research has been a paradigm for the treatment of cancers generally."

Mrs. Giusti, too, has benefited from improved research:



Judith Psenicka for The New York Times

Kathy Giusti with her children, Nicole, 6, and David, 4. Ms. Giusti has cancer and founded the Multiple Myeloma Research Foundation.

Her myeloma, which is classified as "smoldering" or inactive, is being treated with the medication Aredia, which builds bone density.

News of new treatments is disseminated rapidly on the foundation Web site.

The foundation also has a scientific advisory board that includes internationally prominent myeloma researchers; Mrs. Giusti also has helped determine a government research agenda for blood cancers, serving on an advisory board of the National Cancer Institute.

Her hard-driving personality and Harvard degree have helped her. But despite her pedigree, she flunked the university's course in entrepreneurial management. She never pictured herself an entrepreneur. But others do: the Harvard Business School Club of Greater New York awarded her an Entrepreneur of the Year award for 2001.

She was moved by it, but not as moved as the day her daughter asked her why she had to go to work. "Some people get sick," Mrs. Giusti told her. "Mommy raises money to find a cure for those people." Her daughter hurried to her piggy bank and emptied it. She handed her mother the change and said sympathetically, "I hope they get better soon."

Mrs. Giusti has not told her daughter about her illness. She is waiting, and pushing, for a cure.

"My hope — or maybe it's a dream — is that by the time I can tell her, maybe I can tell her then that it will be O.K.," she said. "But I can't tell her that yet."

More information on multiple myeloma may be found at the organization's Web site at multiplemyeloma.org