

Lifesaver

Kathy Giusti believes medical breakthroughs shouldn't be left to chance. To prove it she's raised **\$175 million for multiple myeloma**, the disease she fights every day.

by TIMOTHY DUMAS

Kathy Giusti, founder and chief executive of the Multiple Myeloma Research Foundation (MMRF), is a trim woman of fifty-two with an elegant sweep of blonde hair, hypnotic blue eyes and a joyous, almost girlish, laugh. As she tells of hard-won progress against multiple myeloma, one would never guess that Giusti herself received the blood cancer's irrevocable death sentence sixteen years ago.

Until January 1996 her life had been close to perfect. Giusti was then a rising pharmaceuticals executive living happily in Lake Forest, Illinois, with her husband, Paul, and eighteen-month-old daughter, Nicole. But the doctor's message sounded vaguely portentous: "Come in and let's discuss your blood test results—bring your husband." Kathy reached the doctor by phone while driving down the Kennedy Expressway in Chicago. "Just tell me what it is," she demanded. "You wouldn't have left that message unless something was wrong."

Though Giusti would learn later that her grandfather had died of multiple myeloma, this mouthful of syllables meant nothing to her at the time. "What are the odds?" she asked. The doctor paused and then said, "It's a really tough disease," but would offer nothing further on the telephone.

The next morning, en route to the doctor's office, Kathy and Paul stopped at a local bookstore to do a little research. "We were scouring *Harrison's Principles of Internal Medicine* for anything we could find on multiple myeloma," she recalls. What they found was devastating. "It basically said the disease was 100 percent fatal, and if you were lucky, you'd live three years. I sat on



Kathy Giusti with her husband, Paul, their daughter, Nicole, and son, David, who was conceived after Giusti was diagnosed with cancer

the floor with my husband, tears rolling down my face."

Bone marrow biopsies confirmed the grim diagnosis. It was then that Giusti made an extraordinary decision: to try to conceive a second child. "There was nothing to hope for," she explains. "So I'm looking at my life saying, 'OK, what am I going to do with three years?' I know it sounds crazy, but I didn't want Nicole to be an only child. So there I am, interviewing oncologists and fertility specialists at the same time." In May 1997 David was born. "I couldn't be sad a single day after that."

Now that Giusti had her two children, she could focus on a secondary, long-shot goal: to spark new myeloma research. She'd discovered that because the cancer is rare (as most forms of cancer are), scientists and pharmaceutical companies had only faint interest in exploring cures. In

stark business terms, bringing a new drug to market takes ten years and costs a billion dollars; uncommon cancers are thus seen to lack sufficient numbers to support such a massive investment. And scientists can't get grant money to start labs. The dimmest of silver linings was that multiple myeloma was getting less scarce by the year: some 20,000 people in the United States will contract the disease in 2012 and 11,000 will die from it. From Giusti's own vantage point, she hoped to extend her life long enough to carve out a place in her children's memories. There was also the question of heredity. "We still don't know for sure whether myeloma runs in families," she says. "But I just didn't want to leave the world thinking that, if it did, I hadn't at least done my part for the next generation."

In 1997 the Giustis moved to New Canaan to be near Kathy's twin sister, Karen

So powerful an agent for change has Giusti become that in 2011, *Time* magazine named her to its list of the 100 most influential people in the world, alongside the Obamas and Oprah



Giusti with friends and supporters at the MMRF's fall gala (left), which raised \$2.1 million for research, and with the MMRF team at the recent ING New York City Marathon (below)

Andrews of Greenwich. Each sister is a dynamo in her own right—Giusti graduated from Harvard Business School before her swift rise up the corporate ladder, and Andrews was an in-house counsel at Time Inc. Together they proved invincible. In October 1997 they hosted their first multiple myeloma fundraiser, a gala dinner at the Hyatt Regency in Old Greenwich that fetched the happy sum of \$450,000, most of which the sisters parceled out to researchers. (Today this glittery event nets over \$2 million annually. For more information see page 38 in this issue.) What money remained they used to set up the Multiple Myeloma Research Foundation.

Here a revolution began. “Back in 1998, when people started foundations they had huge hopes and aspirations, but they would do things like start support groups or write brochures,” Giusti says. “I didn’t want to do those things. I wanted to get new treatments to myeloma patients as quickly as possible.”

The MMRF, headquartered in Norwalk, operates like the fittest of Fortune 500 companies; indeed, Kathy’s speech is peppered with terms like *incentify* and *return on investment*. Still, the foundation faced the daunting task of fixing a drug-development system that was “essentially broken,” Giusti says. Myeloma researchers worked in isolation, with little money and few tissue samples to draw upon.

The MMRF arranged a consortium of research institutions, requiring them to share information and publish their weightier findings jointly. The incentive? There were research grants and access to an MMRF-created tissue bank—a scientists’ feast of plasma cells—permitting a much clearer view into how the disease works on a genomic level. This, in turn, sped clinical trials, to the delight of pharmaceutical companies.

“We’ve raised a total of \$175 million,” Giusti says. “For that amount of money, here’s what myeloma has seen: four drugs approved by the FDA and eight drugs currently in Phase III clinical trials. We’ve launched thirty-one clinical trials, sequenced the myeloma genome, and have more than doubled the lifespan of myeloma patients, from three years to seven.”

Dr. Ken Anderson, Kraft Family professor of medicine at Harvard Medical School and director of the Jerome Lipper Myeloma Center at Dana-Farber Cancer Institute, described myeloma as “uniformly fatal” as recently as 2008. “Myeloma is now a chronic illness in many patients,” he says. “Kathy has turned her own illness into hope for many.”

But her accomplishments spill outside cancer research. “Our models are being emulated by every disease-based foundation out there,” she says. So powerful an agent for change has Giusti become that, in



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Progress has not come without impediments. Drug resistance and short remissions continue to typify the disease. Giusti’s own case, after “smoldering” for a few years, accelerated swiftly in 2005. By then, however, she could avail herself of two new drugs the MMRF helped bring to market, Revlimid and Velcade, as well as a crucial stem cell transplant from her sister. Giusti has been in remission ever since.

“With all of the travel and the challenges of running a growing company, I’m susceptible to viruses,” she says. “I can never forget that I have cancer. I think that’s why I run every morning: to remind myself that I’m still out here and able to do things; to give myself a sense that I’m doing OK.”