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CRUCIBLE

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by Steven Prokesch

Crucible

Transformative events that shape leaders



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Kathy Giusti never had any desire to be an entrepreneur—especially one in the nonprofit sector. She loved working for a big corporation and didn't see herself as a risk taker. In early 1996 she was on the fast track at the pharmaceutical company G.D. Searle and aspiring to be one of the first women on the executive committee when, at the age of 37, she got news that would change her life: She had multiple myeloma, a deadly blood cancer.

The diagnosis led her to start the Multiple Myeloma Research Foundation and the Multiple Myeloma Research Consortium, two organizations based in Norwalk, Connecticut, that have won kudos for helping accelerate the development of treatments for the disease. Both have become models for running medical-research nonprofits in a highly disciplined way. The lessons

from Giusti's story—how she adapted to her new world, constantly adjusted her strategy, and persuaded institutions set in their ways to change—are valuable for anyone contemplating moving from the private to the public sector or abandoning corporate life to become an entrepreneur.

Until 1996, Giusti's career had been zipping along. She'd been a premed at the University of Vermont but after graduation decided to pursue a career in the pharmaceutical industry rather than go to medical school. She became a sales rep at Merck, where she was identified as a high-potential employee. She left to attend Harvard Business School and then went to work for Gillette in Boston. When she married Paul Giusti, an HBS classmate, she moved to Chicago and took a marketing job at Searle.

She quickly attracted management's attention. "It was obvious from an early point that she was pretty special," says Alan Heller, who was Searle's copresident. He describes her as "highly intelligent, highly analytical, and very driven." Other current and former colleagues call her a perfectionist. She played an instrumental role in the launches of two successful drugs: Ambien, the sleep medication, and Daypro, an arthritis drug. She also impressed her bosses by mastering other jobs, including running a sales region—the position she held when she learned she had myeloma.

She and her husband had an 18-month-old daughter and had been trying to conceive a second child. Doctors she consulted found the cancerous plasma cells. She was told that myeloma patients were living, on average, three or four years. There was no cure. "They said, 'You just need to get your life in order,'" she recalls.

Determined not to leave her daughter, Nicole, an only child, Giusti underwent in vitro fertilization. After becoming pregnant with her son, David, she left her job and moved with her family to Connecticut to be close to her twin sister and her in-laws. "I was heartbroken to leave Searle," she admits. "I loved what I did. But when

you're told you're going to die, your first instinct is not to worry about your job. Your first instinct is to worry about your family."

Bringing Rigor to Nonprofits

Giusti extensively researched the treatments for myeloma. She was shaken by what she learned. The drugs used to combat the cancer dated back to the 1960s, and no one was devoting significant R&D resources to it. Myeloma is what is known as an orphan disease. Relatively few people (currently, about 60,000 in the United States) have it. And with the development of a new drug costing more than \$1 billion, on average, drug companies prefer to focus on illnesses affecting much larger populations. Having worked in the industry, Giusti understood that. "I'm thinking to myself, 'What pharmaceutical company is going to want to do this?'" she says.

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When people began donating money to help her, Giusti decided to use it to promote myeloma research at medical centers. "I thought that if we funded research, maybe there'll be something that comes along that will buy me a little more time—at least long enough that my daughter would remember me," she says.

She joined the board of the existing nonprofit for the disease, the International Myeloma Foundation. But its main focus was providing information and support. So, along with her twin sister, Karen Andrews, Giusti founded the Multiple Myeloma Research Foundation in 1998, to raise funds for research and attract more people at academic medical centers to the field.

She confesses that she hadn't had much respect for nonprofits, because she thought most were not professionally

managed. "I wanted people to see that I wasn't going to run some schlocky non-profit. I was going to try to do this right," she says.

That was hardly easy for a self-described "big-company person" who was accustomed to being surrounded by talent and being able to call on whatever support she might need. "The day I start, I'm at a computer in my house, trying to make decisions," she remembers. "I don't have an HR department. I don't have an IT person to call. It was a disaster."

But she quickly realized that she had a powerful personal network that she could tap, including her sister, then a lawyer at Time Inc.; Heller, her boss and mentor at Searle; and her Harvard Business School classmates. An HBS alumni group helped her create her first business plan.

From the beginning, she has insisted that the foundation (and later the research consortium) have detailed strategies

and implement them with discipline. Its current strategic plan for personalized medicine runs 67 pages and lays out nine strategies and 22 programs. The leaders of its 24-member staff hold a strategy meeting every Monday and an operations meeting every Tuesday. Giusti requires the foundation and the consortium to use metrics, benchmarking, and scorecards so that all parties know their individual and collective performance and strive to do better. "Kathy was selling ROI to donors two years into the foundation," says W. Dana LaForge, chairman of the foundation's board and a partner at a private equity firm. Giusti's approach has helped her attract and retain talent from industry, such as Louise Perkins, the foundation's chief scientific officer, who spent 16 years at pharmaceutical companies. "What

was clear from the moment I walked in the door was that this place operated in a way you wouldn't expect of a nonprofit," Perkins says.

Collaborating to Conquer New Challenges

To date, Giusti has raised more than \$165 million for myeloma research—an extraordinary achievement given that the vast majority of U.S. nonprofits never break the \$1 million mark. What makes it even more impressive is that she is an introvert by nature. "She's not someone who is really comfortable in the limelight," says Scott Santarella, CEO of the Bonnie J. Addario Lung Cancer Foundation and former COO of the foundation and the consortium. When Giusti is preparing a speech for a gala event, she puts at least 100 hours into rewriting and rehearsing it, he adds.

Fortuitously, shortly after Giusti launched the foundation, thalidomide, a drug used to treat leprosy (and famous for causing birth defects in the late 1950s and early 1960s, when it was prescribed as a sedative, a painkiller, and an antidote to morning sickness), was discovered to have an impact on myeloma tumors. A couple of years later, a new proteasome inhibitor proved effective. Interest in myeloma among academic researchers and biotech and pharmaceutical companies grew substantially. But Giusti then saw that competition among the scientists and clinicians was becoming a major obstacle to drug discovery and development. She realized that the only way to get these players to collaborate was to form a community to which they felt they had to belong—one that allowed them to do things that they couldn't on their own.

Toward that end, she forged close relationships with myeloma experts who shared her vision at four prestigious institutions—the Dana-Farber Cancer Institute, the Mayo Clinic Cancer Center, the H. Lee Moffitt Cancer Center & Research Institute, and Princess Margaret Hospital. Together, they drew up a plan for a

research consortium and persuaded their institutions to join it.

The centers agreed to publish their research findings together, set benchmarks and metrics for conducting phase I and II clinical trials, pool data, and build a state-of-the-art bone-marrow and blood-cell bank that researchers could tap. In addition, the consortium—whose membership has grown to 16 medical centers and community hospitals—conducts clinical trials of promising drugs in companies' pipelines. The foundation's database of myeloma patients makes it easier to recruit patients for the trials and helps the consortium attract pharmaceutical and biotech firms seeking to run them.

Though most nonprofits never break the \$1 million mark, Giusti has raised \$165 million for myeloma research.

"What Kathy brought to the table was an unwillingness to accept the norm," says Keith Stewart, dean for research at the Mayo Clinic in Arizona. "She's a demanding person. She knows what she wants, and she doesn't rest until she's found a solution to thorny problems."

There are now four FDA-approved drugs for treating myeloma, and six more are in phase III clinical trials. Giusti's organizations played a role in almost all of them. The average life expectancy for people with the disease has doubled to seven years.

Though myeloma eventually kills everyone who has it, the newest hope is that genomics and personalized medicine will produce breakthroughs. In typical fashion, Giusti has plunged into systematically learning not only the science but also who the best potential partners are. She has enlisted the Broad Institute and the Translational Genomics Research Institute to sequence the myeloma genome. One

discovery: There are a number of kinds of myeloma.

Giusti learned that she had one of the deadliest varieties. Her disease, which had been asymptomatic at first, became active in 2005. After drugs proved ineffective, she underwent a successful stem-cell transplant from her sister in 2006 and remains in remission. "One of the legacies of the transplant is she is susceptible to bugs," her husband says. "I think people sometimes don't recognize how hard it's been to do what she's done."

Giusti regularly works 12-hour days and every weekend. She has taken only three months off, when she had the transplant. "That's just part of being an entrepreneur, right?" she says.

By all accounts, she holds herself and her employees to extremely high standards. Her litmus test for both staff and partners is their dedication to helping patients and their drive and ability to produce results. (All job applicants are put through a personality assessment.) "She's not a touchy-feely manager," her sister says. "It's not her style. To work in an incredibly winning organization and to be treated with respect is what she looks for and what she expects her employees to look for."

Giusti admits that she had trouble believing that people who didn't have myeloma could share her sense of urgency. "But I have learned that there are people equally as passionate as I am about finding a cure," she says. "They may be passionate in a different way, but they want to get it done. Those are the people I trust."

Can she trust someone enough to let him or her take over her organizations? Clearly, this is a big challenge for her. Giusti, who is 52, recognizes that succession planning is important. "I know I can't do this forever," she says. "I know a relapse is inevitable." But those close to her have trouble imagining her handing over the reins completely, because there is still no cure for her disease. ♡

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