

Patient Power

After being diagnosed with cancer, Kathy Giusti created a foundation to help others with the same disease.

Written by Leah Morrison

Photos courtesy of Kathy Giusti, except where noted



Giusti and attendees at the HBS Kraft Precision Medicine Accelerator Roundtable

Giusti at the Multiple Myeloma Research Foundation Fall Gala

In 2006, Kathy Giusti flew to California to participate in a medical panel, hosted by Michael Milken, focusing on the perspective of cancer patients. Giusti was excited to be part of the discussion, which also featured athlete Lance Armstrong and philanthropist Eli Broad. It marked an important milestone for her, which went hand-in-hand with the panel's topic: Giusti, at the time, was a cancer patient living with multiple myeloma—a cancer that forms in plasma cells and accumulates in bone marrow, producing abnormal proteins, that cause kidney problems—and had just received a stem cell transplant from her twin sister.

Giusti with former Vice President Joe Biden and Dr. Jill Biden at the Cancer Moonshot Summit



"I had been in isolation for months and months, and had been so sick, and [the panel] was my inspiration—my very first day back was flying all the way across the country, bald as can be—I think I weighed about 95 pounds—and it was the first thing I did," she recalls, mentioning that she has been in remission for 10 years.

She adds that people couldn't help but look at her and know she was going through something—it was obvious from her appearance—but what people couldn't tell was how her diagnosis had led to her becoming an expert in the field of myeloma and how her foundation is eradicating the disease.

Giusti grew up with an identical twin, Karen. They were best friends and the companion each other came to rely on. "The great thing about it was also that we weren't really competitors—we always wanted each other to be at the same level," Giusti says fondly. "We were constantly lifting each other throughout the years, [as children], and to this day she's still my closest friend."

It was with Karen that Giusti founded the Multiple Myeloma Research Foundation (MMRF) in 1998 after being diagnosed with the disease three years before. Following her diagnosis, she discovered there was little research being done to create drugs and therapies for patients living with myeloma. She couldn't believe an entire form of cancer wasn't being championed, especially one that could be so aggressive—Giusti's own doctors had warned her she had little time left.

Living with myeloma, Giusti had a window seat to what healthcare systems look like from a patient's perspective. She explains how there were various moments where she would question why things were carried out in a certain way. She began identifying challenges and thinking about how to remove obstacles that would lead to beneficial results.

Told she only had three years left to live, Giusti felt a tremendous urgency to move those obstacles and find business models to solve them.

"Scientists need to get grants, they need to get funding," she says. "You're not going to get them to come over and play unless you do that. So that told me on day one that if I wanted a disease group that was going to focus on research I had to raise the dollars."

She set to work, relying on her business experience working in the pharmaceutical industry to help move her forward toward her goals. Though she had met with various nonprofits in her career, most of them were focused on education and policy rather than science and research, and many were not able



to raise the kind of funds she thought were needed to pursue new therapies and cures.

"Nonprofits—when I was starting—were more like mom-and-pop than they were about building a corporation," she clarifies.

Giusti began with her Harvard Business School community. "I reached out to every classmate and anyone I could find to lift me off the ground and get the funding out there."

After getting grants done and welcoming scientists on board, she realized that teamwork doesn't necessarily come easy. "I might say to them, 'Why don't you work on this collaborative grant together?' And even with that there would always be one who was the superstar, and he'd say to the others, 'Come along with us.'"

She confesses that the scientists weren't being held to clear milestones, so she decided

L-R: Giusti, Robert Kraft, Jonathan Kraft, Harvard Business School dean Nitin Nohria, and Professor Richard Hamermesh

to create collaborative models on which the foundation would run. The result was a virtual tissue bank that numerous centers have access to and share. Once the bank was established the foundation started piquing the interest of others intrigued by Giusti's sharing methods, including Eric Lander, a mathematician, geneticist, and professor of systems biology at MIT.

After hearing him speak about The Cancer Genome Atlas (TCGA) at a conference, Giusti approached Lander and expressed her concern that it would take a long time for anyone to do the work he spoke of in the field of myeloma, and offered her services to work with him at the Broad Institute (where he is the president and founding director). "He said he needed this many samples, myeloma expertise, and this amount of funding," she says of Lander's response.

She provided him with everything required and the two became the first people to sequence the myeloma gene. They were happy, but realized how hard it was to get academic centers to share their data. "We decided that we would launch a compass study—which was probably one of our biggest initiatives ever—and that's where we do genomic sequencing... and it's [now] the largest genomic data set in the world," Giusti explains.

There is now a clinical network comprised of more than 20 centers that continue their research, run clinical trials, and share their data, which resulted in 10 new drugs available for myeloma patients.

Learning from her experience with mom-and-pop foundations from the early days of her career, Giusti continues to run MMRF on a strict business model where people of all kinds collaborate to reach the same goals.

"Set the strategy and make it audacious and identify the partners who will be audacious with you—you know, the people who are really passionate about the patients, the people who are willing to raise their hand and be the first movers. When you can surround yourself with people like that, you'll find the community will work with you in a really thoughtful way," she notes, adding that understanding how funds will be invested is also key. "If you can give everybody access to funds, a strong strategic plan driven with good audacious milestones...bring the best partners together and let them hear the voices of the innovators. It's amazing how you can rally a whole community around doing strong innovative things that people wouldn't have thought about."



Giusti and her sister
Karen Andrews

Having survived her odds of living with myeloma—she has been in remission since shortly after her stem cell transplant—Giusti knows she is in a unique position to advise and interact with patients, admitting she is vastly empathetic with those living with the disease. (Giusti herself gets tests done every two months to make sure her own health stays on track, and confesses it's nerve-racking each time.) The patients she sees on a day-to-day basis are typically newly diagnosed or have relapsed and run out of options and are struggling.

She is a strong advocator for patient engagement, advising those living with myeloma to speak with as many experts as possible to get the broadest and most interesting perspectives in order to generate strategic plans for getting better.

"How do you solve a problem when the people who can fix it don't know there is a problem?" she asks, mentioning that many patients believe their case data is being shared between centers and facilities for experts to suggest the best plan of action.

"Of course doctors want the best for their patients—and they do! It's not like the doctors are holding the data back; it's the system and the incentives that have gone awry. Most patients think—because they love their doctors and they love their centers—of course their data is being shared and it's out there in a thoughtful way. And it's not, and I think it's one of the biggest obstacles to a cure."

Because there is currently no cure for myeloma, 25 to 30 percent of patients pass away within the first three years of their diagnosis. This reinforces Giusti's belief of the importance of open-access sharing within the medical community.

"I really want to build data systems where anybody in the community—any community of oncologists that has a myeloma patient—could go into a database that we're sponsoring and be able to say, 'My patient looks like this: They're African-American,



Children David and Nicole with Giusti and her husband Paul

PROFILE
KATHY GIUSTI

they're over 60, they're whatever', and really be able to understand what we've learned and how to treat that specific patient and that specific subtype, and down the road be able to democratize that care so every patient is getting that kind of care," she says.

Giusti's expertise and strategies have caught the eye of others in the field, including Robert and Jonathan Kraft (respectively, CEO and president of the New England Patriots). They gave a \$20 million endowment to Harvard Business School within the field of precision medicine and appointed Giusti as co-chair of the Kraft Precision Medicine Accelerator, where she works to apply her models designed for myeloma to other kinds of cancer.

She continues to have admirers and partners in the medical field, including Michael Milken, and deems the panel she partook in immediately after her transplant to be her most memorable meeting with him. "It was his pure kindness through that whole event

that really touched me. Because that doesn't come naturally to everybody."

She mentions how critical it is to have the support of a public figure who shares her views and ideals. Milken is fixated on curing cancer, and the fact that he is known to rally those of a like-mind and work toward building solutions is something Giusti says is joyful. "I look at people who have worked with Mike, whether it's Margaret Anderson or Greg Simon, and I think we all have felt it. As patients—Greg was one, Mike was one, I was one—we know that cures can be found and we want it to happen faster than it's happening right now. That's what I love about him. He has that same level of urgency that we do."

She continues to work with him through *FasterCures*—a center based in Washington, DC that aims to save lives by improving the medical research system—and often works with teams he has put together.

"Don't wait," she advises, a note of seriousness in her voice. "If you have a great idea and you think it's critically important to get it done, don't hold back and don't wait...If you think it's the right thing to do, go with your heart. Do it. Make sure you're prepared, but take the risks, go, and know that if you do and it's not right it's okay. Just reset and start again." **LM**



For more information about the MMRF, visit www.themmr.org

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