

# NEW CANAAN DARKEST & ROWAYTON

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**Kathy Giusti**

on family, friends  
and finding a cure for  
multiple myeloma

# Life Triumphant

Twelve years ago **Kathy Giusti** was diagnosed with multiple myeloma and given no more than three years to live. Since then she's raised more than \$100 million for research and this month will celebrate Christmas with her family.

On a sunlit day in late summer, toilet paper flutters in the breeze, draping Kathy and Paul Giusti's usually pristine New Canaan home. The traditional welcome accorded rookie team members by New Canaan High School's varsity cheerleaders honors their daughter Nicole, who, fresh from Saxe Middle School, has just made the squad.

Meanwhile, a victory barbeque for David Giusti's Cal Ripkin all-star baseball team is scheduled for later that evening. Coached by Paul, New Canaan's ten-year-olds came in eighth in the nation after a summer of intense competition. Paul waves happily to his wife before heading into the kitchen to cook chicken drumsticks for what will be a major celebration.

Cheerleaders, a dad and his son playing baseball — what looks like a perfect slice of suburban Americana is not quite that simple. “I have to pinch myself to believe this is real,” Kathy says. “I never thought I would live to see my daughter start kindergarten.”

Diagnosed with multiple myeloma in January 1996, when Nicole was eighteen months old, Kathy, then age thirty-seven, was told she had from three months to three

years to live. David, today's baseball all-star, was conceived after the diagnosis. “I so badly wanted my daughter to have a sibling,” Kathy says, “and my disease was still inactive.” When they got the medical go-ahead, Paul did not need to be persuaded. “Being pregnant was a ray of sunshine during those dark days,” Kathy recalls. Their son's birth in May 1997 was life triumphant in the face of a looming death sentence.

At that time Kathy was a senior executive at the former G.D. Searle & Co. and knew her way around the pharmaceutical landscape. It didn't take her long to confirm that research was at a standstill — there were no drugs in the pipeline for multiple myeloma.

Seeking answers, the first person she called was her identical twin, Karen Andrews, who did not have the disease. According to Dr. Ken Anderson, director of the Jerome Lipper Multiple Myeloma Center at Boston's Dana Farber Cancer Institute, the sisters' situation is very uncommon. A comparison of their plasma cells revealed genes that are identical. “But sort of like a circuit box, certain ones are turned on and others off in each twin,” he says.





“You don’t get things done by yourself; people lift you up and then the impossible becomes achievable.” — Kathy Giusti

The Giusti family at home — Kathy and Paul with daughter Nicole and son David

Karen, an attorney who lives with her family in Greenwich, and Paul supported Kathy until she was able to help herself. When word got out, there was a groundswell of support from friends and neighbors who kept calling, wanting to know how they could help find a cure. A fundraiser in October 1997 raised more than \$450,000.

A few months later, in 1998, the sisters established the Multiple Myeloma Research Foundation (MMRF) to jumpstart a more aggressive approach. “Our goal was to get new drugs approved,” Kathy says. “Back then many foundations were very touchy-feely, more into offering support groups and sending out newsletters; we wanted to address the science of it and the process.”

Now, a decade later, Kathy and Paul look back on those early days with a sense of profound appreciation for what they call “the sheer humanity” of the town they live in.

“New Canaan was behind me from the very start,” Kathy says. “You don’t get things done by yourself; people lift you up and then the impossible becomes achievable.”

Kathy was convinced that a much more aggressive approach was needed. In 2004 she created the Multiple Myeloma Research Consortium (MMRC) despite outspoken opposition to what was then the radical idea of getting researchers and major medical centers to share information. “People told her it would never work,” Karen says. “They said she was crazy to try.”

Being both cancer patient and groundbreaker was stressful, but Kathy felt she had no choice. “Nobody really understood how broken the system was for research and drug development in oncology,” she says, pointing out that it still takes much too long to get a new drug to market. “Meanwhile, people, especially those with

uncommon cancers, are dying.”

Tradition had it that researchers worked on their own and medical centers and pharmaceutical companies competed with one another. The “publish or perish” norm meant that scientists, often unwittingly, duplicated what others had already done.

Involvement with the National Cancer Institute was an eye-opener. In an arena where advocates for a whole range of different cancers are trying to get NCI support, the one thing they all agreed on was the need for a consortium to promote cooperation among academic centers. “The NCI couldn’t handle it,” Kathy says. “They are not businesspeople. With my MBA from Harvard, I had the background to do the job.”

Funded by the MMRF, which has raised more than \$100 million in the past decade, the consortium’s mission is to fast-track therapeutic options by providing business solutions to scientific problems. Working with a health-care consulting firm, Kathy laid out a full operating and business plan designed to answer two simple questions: What is the barrier, and how do we fix it? The goal, says Kathy, who is CEO of both the foundation and the consortium, is to eliminate obstacles so that novel drugs move quickly from laboratory bench to patient bedside.

The fledgling consortium started by convincing four of

## what is multiple myeloma?

Multiple myeloma is an incurable cancer of the plasma cell that afflicts twice as many men as women; African-Americans; and, usually, people over sixty-five. Because it is an “orphan” cancer affecting a population too small to attract the interest of big pharmaceutical companies, the outlook for patients was grim. In 2008 an estimated 19,900 adults in the United States were diagnosed with the disease and an estimated 10,790 died from it.

the top cancer centers in North America that coordinating high-quality clinical trials, setting up standard procedures and creating a centralized tissue bank would benefit their research programs. The Dana Farber Cancer Institute, Mayo Clinic, H. Lee Moffitt Cancer Center and UHN/Princess Margaret Hospital were the first to join the MMRC. The late writer and filmmaker Michael Crichton, whose mother lives in New Canaan and who had a family member with myeloma, gave the consortium half a million dollars to create the tissue bank.

Today fifteen major academic centers comprise what is now hailed as a new model for how scientific research can be done better and faster than before. “Collaboration is key to accelerating development of treatments that can prolong life until ultimately we find a cure,” says Dr. Anderson, who has been researching multiple myeloma for the past thirty years. Among the founding MMRF and MMRC board



Supporting Kathy’s fundraising at the 2005 MMRF gala — Ann Curry, Brian Williams, Deborah Norville and Alan Panzer



CONTRIBUTED PHOTOGRAPH

Kathy and last year's MMRF gala honoree, cancer survivor Lance Armstrong

## new treatments

Four new treatments — Thalomid, Velcade, Revlimid and Doxil — are now available to myeloma patients, whose survival rate has doubled as a result. According to Dr. Ken Anderson, director of the Jerome Lipper Multiple Myeloma Center at Boston's Dana Farber Cancer Institute, "In many patients it's fair to say that myeloma is a chronic disease that can be controlled by medication for many years."

Velcade and Revlimid are being used by patients with other hematologic, or blood, cancers as well as solid tumors. There are currently thirteen clinical trials being facilitated by the MMRF/MMRC.

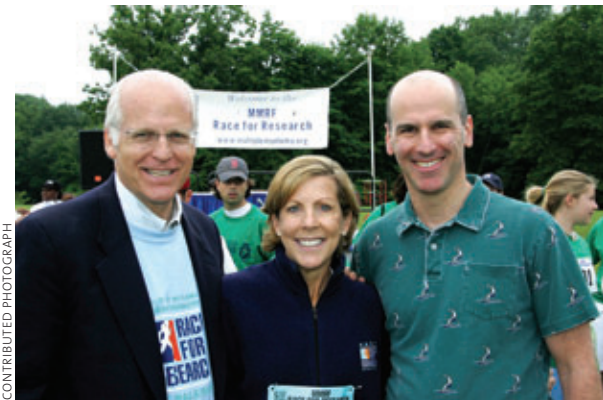
members, he has been quarterbacking Kathy's care dating back to the earliest days. "He's more than just my doctor; he's a kindred spirit and dear friend," she says. "We both understood from the beginning what had to be done."

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The MMRC's steering committee, comprised of three myeloma researchers from member institutions, advises Kathy on which experimental drugs should move forward into clinical trials; a team of scientists evaluates the committee's recommendations. The selected clinical trials are funded, and participating centers are given help recruiting patients and obtaining approvals from affiliated hospitals. A coordinator is provided on-site to solve whatever problems might develop.

"We offer money, manpower, expertise and access to patients through our database, as well as myeloma blood cells and bone marrow from our tissue bank," Kathy says. A necessarily stringent grant-review process asks researchers to specify expected milestones. "Of course, sometimes the unexpected can lead to a breakthrough," she adds. "Everything is considered, but we don't automatically cut the next check. We need to get the most out of every research dollar."

Kathy's heart is focused on each and every patient, but her business approach is strictly Fortune 500, drawing media attention in this age of venture philanthropy. CBS, NBC, CNN and other networks' prime-time news programs, as well as publications ranging from the *New Yorker* to the *Wall Street Journal*, have given her national coverage. A recent article in *Forbes* called the



CONTRIBUTED PHOTOGRAPH

Joining Kathy at the MMRF Race for Research were longtime supporters Congressman Christopher Shays and Michael Bar.

MMRF/MMRC “a force to be reckoned with,” while *Time* magazine described her pay-for-results funding model as having “more to do with Silicon Valley than Big Pharma.” At the same time, it noted that in four years, the MMRC has significantly speeded up a drug development and rollout process that formerly took a decade.

“Nobody understands better than I do that pharmaceutical companies have to answer to their shareholders; so do we,” Kathy says. “Our shareholders are the patients.” The MMRC team of scientists keeps track of experimental drugs invented by pharmaceutical and biotech companies. If a compound looks promising to treat myeloma, the consortium approaches the company, offering to cover the costs for testing it at an MMRC center and then funding clinical trials should they be appropriate.

Being tough in order to get results comes with the territory. “These days we have the clout to cut through bureaucratic red tape,” Kathy says, pointing out that the MMRC tracks the clinical trials it supports. “We do a scorecard charting how long it takes to develop the protocol, write the contract and then get through the Internal Review Board. And yes, there have been times when we’ve walked away because the academic center took too long to review a grant contract. We don’t have time to waste here.”

**K**athy knows exactly what it feels like to be a cancer patient desperately in need of the next new drug. In March 2005 Dr. Anderson gave her the bad news that the latest blood test showed that her disease had become active. By April she was being treated with one of the new drugs that the MMRF/MMRC had helped get to market, but she was unable to achieve a complete response. By Thanksgiving the decision was made to transplant stem cells donated by Karen. Kathy began a regimen of Cytoxan, a powerful chemotherapy drug, in preparation for a January transplant.

Lori Marcus, an MMRF board member and close friend, recalls Kathy’s birthday celebration that year at a local spa. “During the massage, her hair began to fall out in



Kathy and Paul Giusti — a shared bond

clumps and the masseuse thought she’d caused it,” Lori says. “Kathy calmed the woman down, then found humor in what had occurred. She somehow made laughter possible, which was the best antidote.” Kathy remembers it a bit differently. “Thank goodness for my girlfriends — they got me through it,” she says.

Supporting Nicole, then twelve, and David, then nine, was her first priority. “They’d known I had cancer for about two years by then and that I had to have my blood tested every two months,” she recalls. “Paul and I told them because we didn’t want them to find out by accident, given that I was frequently in the local newspapers.”

As Christmas approached Kathy decided to shave her head. “I took David along because it was a good chance to talk with him,” she says, recalling that they went grocery shopping afterward. The idea was to keep everything as normal as possible, including going on a scheduled family ski trip in early January. “I wore a helmet with a hat over it,” Kathy says, “and I skied the course.”

Close friends were not at all surprised. “She has not allowed this disease to define her,” says Lori, “or stop her from being a hands-on mother. She’s been class mom, a volunteer at their schools and she’s always there to cheer whatever sports team they’re on. Many of us have gotten to know Kathy just sitting together on the bleachers

watching our kids play. If you didn’t know she was sick, you’d never guess it.”

Shortly thereafter it was time to leave for Dana Farber to do the final chemotherapy preparation for the transplant. “I remember David hugging me before I left,” Kathy says. “Mommy,” he said, “I am so scared you’re going to die.” And the truth was, it was entirely possible. “With a transplant,” Kathy says, “there is no guarantee.”

In an essay Nicole wrote shortly after visiting her mom at Dana Farber, she describes slipping into the room wearing gloves and with her mouth and nose tightly covered to guard against spreading germs. “Despite a balding head and a failing immune system, my mom manages to put on a smiling act to make me feel safer,” Nicole wrote. “I throw myself into her arms and hold on as if I could never let go.”

After the transplant on January 23, 2006, almost exactly ten years after the diagnosis, Kathy was struggling. Paul and Karen were taking turns staying with her at the hospital. Slowly she bounced back, step by tiny baby step, her new immune system gradually taking hold. “Paul is always incredibly caring, but strict,” she says, “while Karen was a saint by my side, plus she has this great sense of humor, so they were the perfect tag team.”

Messages of encouragement flooded Kathy’s CaringBridge website. “Friends from all phases of my life found me,” she says. “From January 16 to June 4, 2006, some 10,000 e-mails made me realize how lucky I am to have so many people who care about me.” Two years later, paging through an album of the website compiled by Paul, a gift for Christmas 2007, she says, “Every time I read this, it makes me cry.”

On February 1, 2006, an e-mail from Dr. Anderson and the myeloma team brought Nicole and David the best news of all. “Your mom has turned the corner; she will be home with you again before you know it.” The transplant had worked: Karen’s healthy stem cells were growing, restoring Kathy’s blood cells, platelets and immune system.

Five days later, weighing 102 pounds and “tired from the inside out,” she returned home, where Nicole and David

took charge. Big hugs, games of Scrabble, slow walks around the block, a careful game of catch in the backyard and watching the Olympics together were better than any doctor's prescription.

Looking back, Kathy is still overwhelmed by the way friends and neighbors pitched in to help keep things as normal as possible for her family while she was so ill. "People made meals for us, drove the kids places, arranged sleepovers, went to cheer at all their sports events," she says. "Their teachers were wonderful; I can never thank them enough." While Kathy sees her future as being all about "paying it forward," the many whose lives she has already impacted would say she's been doing that for a long time.

New Canaan resident Kay Luff lost her husband, Jerry, to multiple myeloma this past July. "But he had eight good years after the diagnosis; he saw his son get married and two grandchildren born," Kay says. "That is thanks to the MMRF, which he found on the Internet. He was so reassured that it was right here in town and went immediately to meet Kathy."

Kay recalls that in 2001 Kathy was pretty much holding down the fort, assisted by volunteers who helped with fundraisers. "Jerry went through five different trials. Each time he needed the next magic bullet," she says, "Kathy was able to connect him."

When Jane Williams's cousin's disease was diagnosed five years ago, Jane called Kathy immediately. "To be diagnosed with a fatal malignancy is truly terrifying," Jane says. "For me to be able to connect my cousin with the MMRF was a gift. Kathy jumped in on a very personal level and

arranged for him to see Dr. Anderson."

Jane and her husband, *NBC Nightly News* anchor Brian Williams, are dedicated to helping spread the MMRF/MMRC message, including scheduling a prime-time television interview to help raise awareness. Honored in 2005 with a Leadership Award at the ninth annual Friends for Life fall gala held in Greenwich, Brian Williams is just one of many high-profile leaders who have made Kathy's cause a priority.

Boldface names aside, nothing speaks louder than the size of the crowd that always turns out for the annual Racewalk for Research, a 5K event held every April where up to 1,700 local participants either walk or run through New Canaan to raise money for research. In 2004 Parent-Teacher Council President Amy Rochlin, a friend of Kathy's, urged the schools to become involved.

"I knew Kathy and Paul had recently shared the diagnosis with Nicole and David," she says, "so here were these two little kids who had just been told their mom has this scary disease. We wanted to be there for them, and what better way than to step forward as a community to support what their mom was doing?"

Along with celebrity athletes like Rebecca Lobo and Lance Armstrong and serious runners from all over, thousands of locals show up. Teachers and school principals join families whose lives have been touched by myeloma in calling out their friends and relatives to participate.

Jerry Luff's daughter Kelly Weldon remembers how proud her dad was of Team Luff, made up of generations of family and friends. "He felt that he owed so much to

the MMRF and to Kathy," Kelly says. "He particularly admired the businesslike way she ran the MMRF/MMRC, her determination to challenge the norm and her unwavering focus."

Today, between the two organizations, thirty dedicated professionals share that focus on cancer patients, individually and as a group. "I'm just the CEO," Kathy says. "The people I've been able to hire are absolutely brilliant; they're qualified to make decisions I don't have the background to make, but more than that, they care passionately. I can trust them completely."

That's no small statement from a woman who has a well-deserved reputation for being a sometimes impossible perfectionist. "I can take time off without guilt these days because I know the work will still be done," Kathy says. "It's wonderful that it all does not depend on me."

Although her friends say you would never know it, Kathy admits that she still worries every single day. "This is a fatal disease," she says. "It's not a matter of whether I will relapse, it's a matter of when." Because she's been on all the drugs currently available, her body has developed a resistance to them. "So really I'm back to where I started," she says. "I'm relying on the transplant to hold me, and the next generation of therapies to be available when I need them."

Paul understands but prefers to be more optimistic. "I think early on, we were just wishing that things would go well," he says. "Now, looking back on how much has been accomplished, there really is support for being very hopeful that they may soon find a cure." ❧

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