

Breast cancer survivor launched initiative to fund research hunches



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The first time Mary Beth Gadus had breast cancer she looked at her doctor, renowned oncologist George Sledge, and said, “I vow you’re going to do whatever it takes to keep me alive to dance at my sons’ weddings.”

Her boys were just 2 and 4, but Gadus knew how much her husband had missed his own mother at their wedding a few years earlier. She had died of breast cancer shortly before.

Gadus had no intention of history repeating itself.

Not only did the Carmel resident survive that initial bout with the disease 27 years ago, she has made it through four recurrences since.

“To this day, I still have a cavalier attitude: I had breast cancer, it changed my life, and it’s no big deal,” she said.

But Gadus’ experience with breast cancer could turn out to be a big deal for many other women with breast cancer. It prompted her to start an organization to raise money to fund local research into metastatic disease.

Since Gadus began 100 Voices of Hope in 2008, the group has raised \$850,000. This year the nonprofit is striving to hit the \$1 million mark. Unlike many other funders, Voices of Hope focuses on funding not established research but so-called “hunches” that researchers have, early ideas that they want to test to see whether the concepts bear further work.

“You have some ideas, but you do not have any preliminary data to back it up,” said Harikrishna Nakshatri, co-director of the breast cancer program at the IU Simon Cancer Center and a repeat beneficiary of Voices of Hope. “If you present these ideas to a normal funding agency, like the National Institutes of Health or the Department of Defense or (Susan G.) Komen, they won’t consider this because every scientist who reviews your proposal would like to see there is evidence to back up your ideas.”

Nakshatri was the first scientist to benefit from 100 Voices’ funding. His original hunch did not pan out, Gadus said, but the research he did led him down a different avenue.

That finding led to a preliminary NIH grant of about \$400,000 and a follow-up grant of \$1.2 million and many additional avenues of research.

“Probably my research would not have gone into the direction that it is now if it was not for the 100 Voices,” Nakshatri said. “We can do the experiments which are outside the box, the high-risk, high-reward projects.”

In addition, the funding encourages research into metastatic breast cancer, an area frequently overlooked by other funders. Metastatic cancer refers to a cancer that has spread beyond the original site where the disease was found to other regions of the body.

Gadus, who will turn 63 this week, knows firsthand how much progress medicine can make when it comes to treating women with breast cancer. She views her journey with the disease as a historic timeline of sorts of nearly three decades of medical science.

“I have lived, prospered and thrived through 27 years of breast cancer and four recurrences,” Gadus said. “In that time, modern medicine has gone from barbaric chemotherapy to advanced personalized medicine. Every time I have a recurrence, there’s something new to put me back in remission.”

When Gadus first found a lump at age 36, doctors at first downplayed her concern. She had a mammogram and ultrasound, and her doctors assured her there was nothing to worry about and told her to come back in a year. After all, at the time, doctors didn’t worry about a lump in a woman who was 36 years old, Gadus said.

Then she happened to meet Dr. R. Thomas Schmidt, a breast cancer surgeon with the Breast Care Center of Indiana and mentioned the lump to him. He told her to come by for an appointment.

Even before he biopsied it, he knew it was cancer. Gadus had a mastectomy, and then Schmidt referred her to Sledge for chemotherapy.

The Indiana University School of Medicine doctor told her he would take an aggressive approach. “I’m going to give you chemical warfare,” he said, “because if this comes back, you will not be here to raise your children.”

Gadus underwent chemotherapy, which at times left her so nauseated that she wound up in the hospital. Today she marvels in retrospect. Now, some women can even go out to lunch after chemotherapy, fueled by anti-nausea drugs that negate the side effects.

At the end of six months, Sledge told her the cancer was gone.

“Because I knew so many women who had it once and it never came back, because I had had that strong chemotherapy, I went on about my life,” Gadus said. “The longer you go without it, the more you forget about it.”

Eleven years later, in 2000, when her boys were in seventh and ninth grade, the cancer came back. It appeared in the scar tissue on her right side, where Gadus had had her mastectomy.

This time around, Gadus had radiation to her chest and neck and took Tamoxifen, a drug that had not been used in women with early breast cancer 12 years ago. She took it for four years until the cancer returned, this time in her bone in her leg.

Once more, Gadus had chemotherapy and radiation in her leg and hip. But the bone in her leg had been weakened by the disease and treatment. She wound up needing first two titanium rods and then finally a cobalt femur head to allow her to remain active.

In 2008, Gadus attended a meeting of Impact 100, a local charity to which members donate \$1,000 and then gather to choose an organization that will receive a \$100,000 check.

Some time before that she had attended a talk by Dr. Judah Folkman, a Harvard researcher who developed the idea of treating cancers with drugs that starved the tumors of the blood supply necessary for them to grow. Folkman noted that he accrued more than 20 rejections for grants before he received funding to test his theory.

“I remember thinking how many lives could have been saved if we could have funded his hunch,” Gadus says.

And then she started thinking about the hunches that might be going unfunded in the same cancer center where she had been treated. Voices of Hope was born.

Each year, Gadus gathers her donors. Nakshatri and co-director of the breast program, Dr. Kathy Miller, invite any of their colleagues interested in the grant to send in a half-page proposal in lay terminology and one of similar length written for scientists. About seven to eight people apply each year, and Miller and Nakshatri whittle down the list to three.

Every December women who have given \$1,000 each to 100 Voices of Hope come together to choose that year’s recipient. At the gathering, they also meet with researchers from the IU Simon Cancer Center, a gathering that brings together both the donors and the scientists, said Susanna Scott, assistant director of development at the IU Simon Cancer Center.

“People learn about what’s going on, how complex of a disease cancer is,” she said, “and the researcher gets to hear a different perspective. That is a really nice balance.”

Seven years into 100 Voices, Gadus is hoping that the organization passes the \$1 million mark in funds. Meanwhile, she is grappling with her fourth recurrence of the disease.

In 2013 the cancer returned in one spot in her spine shortly before her older son’s wedding. She underwent targeted radiation unbeknownst to most of her friends and family and danced with her son at his wedding to Rascal Flatts’ “My Wish for You.”

A year later the cancer had returned in her lymph nodes, abdomen, and groin. Doctors biopsied the tumor and chose an oral chemotherapy to specifically target markers present in her tumor. The drug appeared to be working, but it also caused side effects. In June, Gadus entered her first clinical trial, using the same drug in a smaller dose, enhanced by another agent.

Side effects led her to drop out of the trial, but the cancer is no longer detectable.

“Your cancer is stable but insignificant,” Gadus’ doctor has told her. Although he can’t see the cancer, he knows it’s there.

Soon Gadus will start on another drug. She knows she will probably be on chemotherapy the rest of her life. But Gadus, whose first grandchild is on the way, hasn’t lost hope.

“A lot of people who have metastatic breast cancer, they think, ‘I’m going to die.’ I never thought I’m going to die,” she said. “This last time, I thought, ‘I could die sooner rather than later.’ I have always felt that (my doctors) George (Sledge) and now Dr. Bryan Schneider, they’re going to have some new research idea that’s going to put me back in remission.”

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For more information on 100 Voices of Hope and how to donate, visit <http://www.cancer.iu.edu/100voices/>.