

Choosing my own path

Facing a pancreatic cancer diagnosis, I helped devise my own treatment plan and beat the odds.

By Anna Masellis, as told to Kate Ledger

The doctor who broke the news to me in May 2006 was very kind about it. She put her hand on my knee and softly said, "I'm sorry, but we found a mass on your pancreas. The cells are atypical."

As soon as I heard those words, my brain shut off for a moment. I may have shed a tear, but I was speechless. When I went in for the tests earlier that day, I'd known there was a possibility that I had a tumor on my pancreas, but I'd pushed the notion right out of my thoughts. After all, I was a 41-year-old mother of two, I was in excellent shape and I hadn't even felt sick—I thought I had a nagging sports injury. I made an appointment because my squash teammates had me promise I'd see a doctor when I mentioned that this dull pain I'd felt on my right side for the past few months had intensified. I fully expected my doctor to reprimand me for overexerting myself. Instead, when she touched my side, she thought she felt a lump. After results of a CT scan came back as inconclusive, an endoscopic exam and biopsy were ordered, just to be safe.

I didn't need anyone to explain the ultrasound and biopsy results: I have a Ph.D. in medicine, specializing in oncology. I've worked at the Virginia Piper Cancer Institute and University of Minnesota, both in Minneapolis, trying to understand cancer and identify cures. I knew exactly what I was up against.

Pancreatic cancer strikes 37,170 people a year. Sufferers, who tend to be at least a decade older than me, are symptomless or experience only vague signs, such as dull pain, so the disease

is usually advanced by the time it's detected. Most patients die within a year, and that's probably why only 1 percent of government cancer funding goes to pancreatic studies.

Confronting cancer

Despite the dire news, I refused to fall apart, probably because I'd beaten terrible odds before. At age 5, I was diagnosed with Wilms' tumor, a rare pediatric kidney cancer, and underwent several surgeries and an experimental combination of high-dose radiation and chemotherapy. It was such an awful experience that my mother still can't talk about it. But amazingly, the protocol that saved my life then has now become the standard treatment for Wilms' tumor—the survival rate has skyrocketed from only 20 percent to more than 90 percent today. So I knew I had to fight this cancer with everything I've got.

A week later, I went in for a Whipple, the routine surgery to remove part of the pancreas. It was supposed to take seven hours but lasted less than one; the doctors discovered a 3.5-centimeter mass on my pancreas and rice-kernel-sized patches of cancer all over my abdominal cavity. The surgeon gently explained to my waiting family that the cancer had already spread too far to do the Whipple (and further tests would show tumors in my liver). Then he informed them that I might have only two months to live.

My mom took the news hard, which broke my heart, but from what I knew of the disease, I wasn't surprised by the



➤ prognosis. Because of my advanced stage, the oncologist prescribed pain relief and gemcitabine, the most effective drug for pancreatic cancer, which temporarily staves off the disease in roughly 10 percent of patients. But that wasn't going to be enough. From my research, I knew my approach had to be more aggressive—and that it was up to me to find the right experimental treatment plan.

I believed the best thing to do was attack the cancer from multiple angles at once, using a range of drugs. But in order to do that, I needed to find an oncologist who was willing to push the envelope with me.

Uncharted territory

I began interviewing doctors and, within a week, found Gail P. Bender, M.D., who runs a private practice in Minneapolis.

Dr. Bender's overall philosophy is to offer her patients many options, some more aggressive than most oncologists would suggest. She told me she was already treating another patient with an unconventional chemotherapy regimen that included drugs typically used to combat lung, breast, ovarian and colon cancers. I thought her approach made sense, so I decided to work with her, even though chemo with a combination of multiple drugs would be physically brutal. The way I saw it, I'd run a dozen marathons and could push myself to extremes. I could make it through this.

I went through four cycles of chemo. It was grueling, and I was lucky to have friends who cooked for me and drove me to my appointments. Two months later, despite the prognosis, I was still alive. A month after that, in August, I had another CT scan: The mass on my pancreas had shrunk a hopeful 50 percent, and the liver lesions were also slightly reduced. I was thrilled—until I learned that a lesion on one of my abdominal muscles had grown by half a centimeter. Suddenly, my joy vanished; all I felt was devastated.

I went home and thought about what wasn't working with the chemo and, ultimately, figured that the drugs may not have been reaching the inside of my abdomen well enough. I remembered a journal article I had read, which described a procedure in which medicine is surgically delivered into the peritoneal cavity, where it can bathe the tumor cells directly. It's a method Dr. Bender had long used for ovarian cancer, one that only recently became standard treatment for that disease. Dr. Bender and I discussed the idea, and we agreed it was a good approach. The only glitch: We had to wait a month; my body needed to recuperate and build immunity after the last round of

chemo, so I wouldn't be susceptible to infection during surgery.

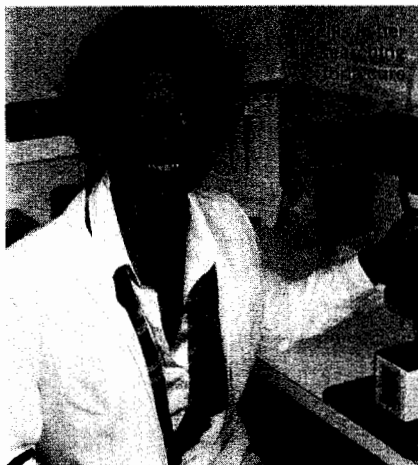
I was so energized to have a new strategy that it was hard to wait. Finally, in October, my surgeon installed a port between my lowest two ribs, where the drugs would be infused. He discovered that, despite the enlarged tumor, every abdominal cancer kernel had been obliterated. Gone! I'll never forget the smile on his face when he told me. I smiled, too—I was making progress.

The abdominal infusions made my belly puff up, and I felt tiny electrical-shock sensations and harsh gastrointestinal cramping that lasted a week. In March 2007, after 18 weeks of treatment, my CT scan showed a clean abdomen. The news was incredible, but I still had a tumor on my pancreas, so I devised yet another regimen of chemo. Our hope was that switching therapies would keep the cancer from becoming resistant to treatment.

It's been a year and a half since I was given only two months to live. The CT scan I had this past August showed no metastatic cancer anywhere, and the primary tumor on the pancreas had shrunk to 2 centimeters and formed calcified plaques, which most likely indicate dying or dead tissue. Even so, I have no delusions: Pancreatic

cancer has a nearly 100 percent chance of recurring. Until that happens, I'm taking full advantage of the time I've been given. I spent the summer in Italy with my kids, I see friends and I pick up my squash racket to play when I can. As a result of this experience, I advocate for other cancer sufferers and help review grant proposals for pancreatic cancer research at the Mayo Clinic in Rochester, Minnesota.

For a scientist, there's no high quite like having your experiment work. That's why I'm helping to write a case study about what I've gone through to share my success with other doctors. I hope my fight against cancer will inch us closer to a cure.



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CLINICAL TRIALS 101 Researchers need to study healthy women to help eradicate future cancers.

You don't have to be sick to help researchers find a cure. To learn about trials near you—and how to enroll in one—visit ClinicalResearch.NIH.gov, www.cancer.gov/clinicaltrials or CenterWatch.com. “If you're interested in joining one, you should ask your doctor for a referral,” advises Patricia A. Grady, Ph.D., director of the National Institute of Nursing Research in Bethesda, Maryland. At right are questions to ask the research team before you decide to sign up.

- What is the purpose of the study?
- What kinds of tests and experimental treatments are involved?
- How might this trial affect my life?
- How long will the trial last?
- Will hospitalization be required?
- What potential costs (travel requirements, time away from work) are associated with the trial?
- Will I be reimbursed for expenses?
- Is there any long-term follow-up care associated with this study?

—Gabrielle Gayagoy