

# THE WALL STREET JOURNAL

## THE JOURNAL REPORT: PERSONAL HEALTH

Essay

### **A Cry in the Dark**

*When a rare cancer strikes, a patient has few places to turn*

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A little over a year ago, my mother went in for what we thought would be routine surgery to remove her gallbladder. Instead, a week after the operation, her surgeon gave her devastating news: She had gallbladder cancer.

My sister called to tell me as I was dropping off my children at school. I sat in my car in the school parking lot, hoping the other mothers wouldn't notice that I was crying.

#### THE JOURNAL REPORT

See the complete Personal Health report. But after the initial shock of her diagnosis, I felt a surge of optimism. As a reporter, I had chronicled the amazing transformation of cancer from a veritable death sentence into what doctors increasingly treat as a chronic disease. Researchers now know more about the biology of cancer and, based on these insights, are developing and testing new drugs that, if not able to eliminate the cancer, can keep it in check. The risk of dying from the disease continues to decline, the National Cancer Institute has reported, and more people are living longer than ever before with cancer. I was hopeful that my mother would be among them.

Determined to help her, I immediately started researching gallbladder cancer. I called oncologists I knew. I did Internet searches and tracked down any paper that I could find that examined the different strategies for treating gallbladder cancer. That's when I discovered a painful reality: My mother and others like her have very few options.

#### **No Entry**

Unlike breast cancer or prostate cancer, cancer in the gallbladder is extremely rare. In statistics kept by the cancer institute, there were only an estimated 7,480 new cases of gallbladder and bile-duct cancer diagnosed in the U.S. in 2005. That compares with more than 212,000 new cases of breast cancer last year, over 232,000 prostate-cancer cases and more than 170,000 lung-cancer cases.

This means that the pharmaceutical companies that drive most of the clinical trials for new drugs in this country aren't paying attention to gallbladder cancer because the market is so small. Single institutions, even those that are major cancer centers, don't usually see enough patients to generate statistically meaningful data, and there is no mechanism to encourage them to pool their data with others. Researchers who are interested in the disease and have creative ideas often find they can't get any funding to test their theories, from either the government or private foundations. As a result, the exciting advances that have transformed the treatment of so many prominent cancers are almost nonexistent in gallbladder cancer.

The implications of this situation hit me at one of our early meetings with my mother's oncologist. My mother's first round of chemotherapy had not stopped her cancer from growing, and the doctor wanted to try another drug. "We understand that this is a rare cancer," I told the oncologist that day. "We're willing to go off the farm." His reply was chilling. There was so little data available on gallbladder cancer that simply by deciding to undergo any chemotherapy, "we're already off the farm," he said.

My mother loves art, and every week she takes a class studying great paintings at the art museum in downtown Boston. When she met with the surgeon who took out her gallbladder, she described the feeling of learning she had cancer as being like the woman in the famous painting by the French artist Georges Seurat, who is painted standing along a river holding a parasol over her head and looking out at the water. Like that woman in the picture, she told the surgeon, "I see cancer over my head all the time."

### **'We're Going to Beat This'**

Still, my mother considers herself a fortunate person. She has a devoted husband and two loving children who live close by. Her many friends have offered to help her whenever she needs it. Living in Boston, we have access to one of the top cancer centers in the country. Her oncologist is compassionate and thoughtful. At each visit, after the doctor has outlined the next step in the treatment, my father always takes my mother's hands, looks in her eyes and tells her, "We're going to beat this." I am the one who sits at these meetings -- my notebook and pen open uselessly on my lap -- feeling angry at the lack of the two things I have always counted on: information and research.

When my mother was diagnosed with cancer, I searched for the right words to comfort her. I finally wrote her a letter. In her fight against cancer, I promised her, "I am and will always be your devoted daughter." I also asked her "not to lose faith that you can make it. I truly believe that you can and you will, and I want you to believe this, too." But the fact is that despite my efforts to find something that might help her, what I have turned up is meager at best.

I recognize that no one who gets cancer -- even a cancer that is more prevalent or better researched than gallbladder cancer -- is guaranteed long-term survival. Individuals with the same cancer can react differently to cancer treatments. And more work needs to be done even in cancers where progress has been made in improving survival. More than 40,000 women still die of breast cancer every year, and more than 30,000 men from prostate cancer.

But people with very rare cancers are denied a crucial tool that other patients get in fighting the disease: the knowledge that researchers are working to find better, more effective treatments and the hope that provides that if luck is on your side and you can endure just a little longer, a better drug may come along that will continue to extend your life.

My mother doesn't get the benefit of either of those things. Whenever the doctor presents her with a new treatment idea, he always tells her that it is her choice whether to try it, especially because he can't give her data that conclusively demonstrate it is even effective in gallbladder cancer. "What choice do I really have?" she always asks me as she steels herself for the side effects of the next drug. She wants to live, and the lack of research means that no one is coming up with any better ideas. In gallbladder cancer, there are no good choices.

## **The Realm of Theory**

When I look back at the notes I took of conversations I had that first week after her diagnosis, I feel again the despair that crept over me. In a prediction that proved true, Melanie B. Thomas, an oncologist specializing in gastrointestinal tumors at M.D. Anderson Cancer Center in Houston, told me that any drugs my mother would get would be "borrowed from other tumors" rather than based on the results of trials involving people with gallbladder cancer. "We're in the realm of theory here," she said.

A surgeon I consulted at the Memorial Sloan-Kettering Cancer Center in New York said apologetically, "There is no good way to say this: No one is thinking about gallbladder cancer."

I am tired of hearing those words. I want others to see my mother as I see her: a cherished person, a life worth saving. She has played bridge every week with the same group of women -- she calls them "the ladies" -- since they were all young mothers together. Even when she isn't feeling well after her chemo, she still works out most days at her health club and runs an adult-education program in the community. And she is always willing to sit on the floor of my children's bedrooms, playing endless rounds of crazy eights and go fish.

The National Cancer Institute is trying to focus more attention on the plight of people with rare cancers. In September, the institute's Epidemiology and Genetics Research Program, along with the Office of Rare Diseases at the National Institutes of Health, hosted a conference for investigators discussing ways to stimulate research on "understudied rare cancers." Edward Trapido, associate director of the institute's research program, said the conference had been prompted in part by his realization that only 28% of funds in his program's research portfolio were spent on cancers in organs other than the lungs, breasts, prostate, colon or cervix.

Investigators funded by the cancer institute's research program were invited to talk about the existing gaps and find ways to do more collaborative projects. This is an excellent and long overdue idea, but even here, gallbladder cancer was overlooked. Since there were no investigators specifically working on gallbladder cancer who were already funded by the group, none attended the meeting, Dr. Trapido said.

## **Companies, Unpersuaded**

I know from my search that there are scientists out there who are trying their best to generate some interest in gallbladder cancer. Dr. Thomas, the assistant professor at M.D. Anderson, has been working with researchers who developed a mouse model of gallbladder cancer, a crucial step in trying to figure out which drugs work best on a tumor. They have promising preliminary data that suggest possible targets for drugs. But Dr. Thomas has been trying for 18 months to get pharmaceutical companies to work with her to develop trials to test novel agents, "with little success," she says.

Anirban Maitra, who runs the biliary-tract cancer lab at the Johns Hopkins University School of Medicine in Baltimore, has managed to build over the years a relatively large repository of gallbladder-cancer tissue. The tissue, from patients' tumors, offers a wealth of potential information, both in finding possible markers of the cancer so it can be

detected before it has a chance to spread to other organs and in helping to figure out better treatment strategies.

But the tissue bank sits unused because there is no funding to study it. Every time one of his researchers wants to test an idea in gallbladder cancer, the lack of money means "I have to think twice," Dr. Maitra says. It upsets me that their hope for a better future is locked away in a laboratory freezer.

At a recent meeting of the cancer lab run by Judah Folkman, the head of the vascular-biology program at Children's Hospital Boston, Dr. Folkman reported that he continued to follow four patients with rare neuroendocrine tumors who had taken an experimental drug. "There will be people who will dismiss the data, saying it is only four patients," he told the other researchers. "But if you ask good questions, you can learn a lot from a single patient. The single patient can make you think differently."

This notion of the value of the single patient is one that I have come to appreciate and admire. Everyone, no matter what cancer they have, deserves a fighting chance.

After my mother's diagnosis, I called Tyler Curiel, the head of the hematology and medical oncology program at Tulane University. I knew that Dr. Curiel's lab had done work on several rare cancers. But that day, I was searching for comfort, not answers.

"A cancer is only rare until you know someone who has it," he told me.

As my mother undergoes another round of chemotherapy, I cling to this idea. It offers the possibility of what I was searching for all along, an avenue of hope. So consider these words an introduction to my mother, Golda Dockser. Now you know someone with gallbladder cancer.