



Their shared ordeal has brought Tomomi and her mother, Keiko, closer



“I’m Too Young to Get Breast Cancer!”

At 31, she learned she’d inherited the “family disease”—and then Tomomi Arikawa found an amazing way to fight it **By Amy Engeler**

On September 2 of last year, Tomomi Arikawa left her office door open as she slipped out to her two o’clock sonogram appointment. She expected to return shortly—the imaging center was just across town from her office at ABC News, where she was a story editor for *20/20*. At her gynecologist’s urging, Tomomi was going to have a tender lump in her right breast checked out. The lump felt squishy, like a piece of Bubble Wrap, not like a hard kernel or a marble or any of the objects tumors were supposed to resemble, so she wasn’t terribly worried. Besides, she

was so young. “I was sure I’d be back in plenty of time to finish going through a stack of newspapers to look for story ideas,” says Tomomi.

It was her first sonogram, and she lay calmly on the table as a technician moved the wand over her breast. “I heard a catch in her breath,” Tomomi recalls. “She looked at me and said, ‘This is routine. I’m going to call the doctor, and she is going to repeat what I just did.’”

Tomomi had hardly had time to consider what “routine” meant when the radiologist came into the room and began to move the wand, concentrating particularly on one area. “I won’t lie to you,” she said. “This doesn’t look good.”

“I knew she thought I had breast cancer,” says Tomomi—“like my mother and grandmother.” She was stunned, as if a huge rock had fallen on her. “I always expected to get the disease. But not at 31.” Her grandmother, Shizuka Okura, had been in her 60s when she was diagnosed, and her mother, Keiko, had been 48.

The doctor showed Tomomi to a private room while she waited for a biopsy to be performed immediately. It was only when she dialed her parents that she dissolved into tears. “Don’t worry, I’ll be right there,” her mom said. “Just give me the address.” The address? Tomomi couldn’t remember where she was. She stumbled down the hallway, sobbing, looking for someone to tell her. Back in the waiting room, she thought about her mother. “I felt I had let her down. I was born four years after my parents had lost a newborn son, and all they’d ever wanted was for me to be healthy and happy.” Tomomi also worried about her younger sister, Miyuki, then 27. *What if she gets cancer, too?*

For the biopsy, the radiologist used a needle to extract five tissue samples. Afterward, she tried to reassure Tomomi, telling her how treatable it would be if it was “something,” but the words just floated around the room. Then a nurse brought Keiko in, “with a look on her face I’d never seen before: extreme worry and guilt and fear,” recalls Tomomi. “That was the beginning of it—I don’t think she smiled again for two months.” The next day, when they learned that the tumor was definitely malignant, was even tougher. At roughly two centimeters (about →

5%–10%
Number of breast cancer cases linked to family history

Tomomi had rejected the idea. *I was just diagnosed with cancer and now I need to think about having children?* she thought. Plus, she worried about the ethics of it. “My grandmother and mom clearly didn’t know about the cancer when they had children—no one can fault them,” she explains. “But I couldn’t see myself having kids, knowing I might be passing this on.”

Dr. Port was reassuring. “There will be better treatment by the time your kids are in their 20s,” she told Tomomi. She also reminded her that pregnancy was at least five years away. Because the cancer was estrogen-positive, Tomomi would be taking estrogen-suppressing tamoxifen for five years, which reduces the risk of recurrence by up to 50%. Tomomi was persuaded; after the mastectomy, she’d undergo one cycle of hormone treatment to harvest and freeze her eggs.

Tomomi and her family arrived at Mount Sinai for the surgery on October 5. The operation was at three o’clock, and two and a half hours later, waking from the anesthesia, Tomomi felt surprisingly normal and relieved.

“It’s over?” she asked. “Thank you,” she said to Dr. Port and her plastic surgeon, Adam Kolker, M.D. And there was good news: The OR exam of her sentinel lymph node, which signals whether the cancer has spread to other nodes, showed it to be free of malignant cells.

Miyuki never left her sister’s room—and, the first night, didn’t sleep at all in case Tomomi needed her. She played music on her iPad that they both liked, especially the song “Chances” from the movie *The Blind Side*. She also took messages and answered the stream of e-mails from Tomomi’s friends and coworkers. But Miyuki kept the mood light: “This is the only time in your life I’m going to be your personal assistant,” she teased. “Don’t count on it lasting.”

Although Tomomi wasn’t planning on going to any nude beaches, she did worry about the appearance of her breast after the mastectomy. Her plastic surgeon had placed a tissue expander under the skin to stretch it. She knew that it could look misshapen, and she wouldn’t complete the

breast reconstruction—when the expander is removed and an implant put in—for several months. Tomomi planned to take her first look at home, “so I could freak out in private.”

“I really loved my breasts,” she says. “To me, they were just right—not too big or small.” But as Dr. Kolker was changing the dressing the next morning, he said nonchalantly, “Here, take a look. Tell me what you think.” Tomomi hesitated at first, then glanced down. “I didn’t feel sad or disgusted or anything,” she says. “Obviously, I had no nipple. But I thought it looked amazing.”

Assuming the worst was over, the whole family accompanied Tomomi to her one-week follow-up appointment with Dr. Port. As they sat down in front of the doctor’s large desk, she explained that a closer look at one of the lymph nodes removed during surgery had revealed some malignant cells after all. This meant the cancer had left the breast. Tomomi had Stage IIB cancer, with an 81% five-year survival rate (without node involvement, the survival rate would have been →

SHOULD BREAST CANCER GENES BE PATENTED?

Because Tomomi Arikawa’s mother and grandmother both had breast cancer, her doctor sent her to be tested for mutations in two key breast cancer genes: BRCA1 and BRCA2. The University of Utah Research Foundation holds the patent on these genes, and the lab that performed the test, Myriad Genetics of Salt Lake City, has the exclusive license to perform the test. The test can cost over \$3,000, plus \$500 to \$700 for a supplementary service called BART that looks for large-scale gene rearrangements. (Tomomi, who tested negative, had to pay for BART, but her insurer covered the main test.)

Beyond the high fees, this monopoly means that women who receive inconclusive results from Myriad or who simply want to confirm the findings generally can’t go for a second opinion from another lab. Moreover, many scientists argue that Myriad’s exclusiv-

ity has held back research into genetic factors in breast cancer, which the company has denied. “They have a huge amount of information, and from the scientific point of view, we feel that as a community we could be pretty smart about figuring out what that information means,” says Wendy Chung, M.D., Ph.D., director of clinical genetics at Columbia University and a plaintiff in a lawsuit brought by the American Civil Liberties Union and the Public Patent Foundation to challenge Myriad’s exclusivity in testing.

In March 2010, the plaintiffs won, with the judge ruling that DNA sequences could not be patented. But Myriad appealed, and on July 29, the U.S. Court of Appeals, in a two-to-one vote, ruled in Myriad’s favor. As *Good Housekeeping* went to press, no one knew what the next steps would be, but it’s possible the case will end up in the Supreme Court.

about 90%). Though not all cases require it, in this instance Dr. Port recommended a second surgery to remove the remainder of the lymph nodes from Tomomi's right armpit. "Sign me up!" Tomomi said, with her usual pluckiness. But she struggled to hold back tears. "I heard my dad take a breath, and my mom was about to start bawling. I kept thinking, *I have to hold it together*," she recalls.

That night, she couldn't sleep. The lymph node involvement upset her more than the original diagnosis had. "For the first time, I realized I could die from this cancer," she says.

In this dark mood, she worried about her future. The next day, she saw a psychiatrist to deal with her distress. "She helped me figure out what I needed to be thinking about—whether having children was a big thing for me or not, for example—and I felt more in control," says Tomomi.

The second surgery went smoothly, and six weeks later, the egg-harvesting cycle yielded 29 eggs to be frozen. Tomomi, who'd taken a leave from her job for the surgery, returned to work in early December. But there were more challenges ahead, including a rough four months of chemotherapy. Sometimes, as she lay on the bathroom floor, overcome with nausea, her sister sat outside in the hallway to be close. The immune-boosting injections Tomomi received caused bone and muscle pain so intense she couldn't stand to be touched, even accidentally. "I thought about how hard it was for my family to watch me," says Tomomi. "They felt helpless."

It was painful, Miyuki remembers. She also worried that the treatment was taking away her sister's optimism. "Tomomi had always been a positive person, and she stayed that way throughout the surgeries. But

during the chemo, I was scared that the experience would somehow change her outlook and personality."

Finally, in late March, all the chemotherapy treatments were done. Tomomi could see the relief on her mother's face: "The death glare was gone." But Keiko knew from her own experience that the next stage—living as a cancer survivor—might be difficult for her energetic, proactive daughter. "The doctors tell you, 'Your cancer is gone; you are finished.' For the woman, though, it is not finished," she says.

Tomomi agrees that she's impatient to get back to "normal," to stop "overthinking things like dating" and what she should tell guys. *Will they understand the consequences?* she wonders. "Mostly, I want to be able to think about my future without focusing on cancer," Tomomi says.

"That is very common," her mother begins, mentioning comments she's heard from members of the Japanese-speaking breast cancer support group she runs. Tomomi interrupts, laughing: "OK, Mom, you don't have to defend me." Her mother smiles. Though they might be opposites in personality, it's obvious that a special bond unites them.

Something else had changed in Tomomi. As she began to reflect on her cancer experience, the idea of children—whether from her frozen eggs or by adoption—began to grow on her, overshadowing her concerns about passing on a breast cancer legacy. "So many people—my family and friends, even people I hadn't known before—have helped me through this," says Tomomi. "It's shown me that if someday I can give life in some way, and if that person experiences the same love and happiness I've been embraced with, she will be very lucky." ■