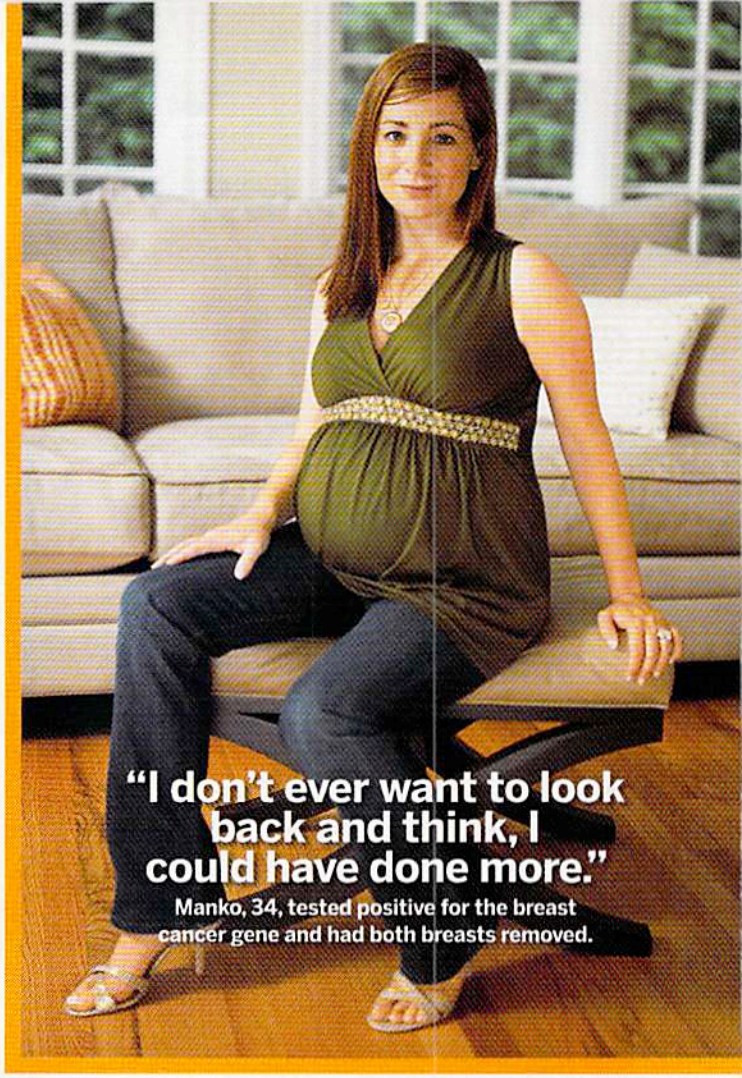
Breast cancer in the family



These cousins share a scary history, but they made opposite choices. How far would you go to lower your risk?

Marni Manko had perfect breasts. Whether sheathed in a turtleneck or swelling from a bikini, as a pair of C-cups adorning a 5-foot-3-inch body, they unfailingly attracted notice. "I thought they were my best feature," Manko admits, giggling. "They looked good!" A vivacious 34-year-old with green eyes that widen as she speaks, Manko is the picture of health. And yet a little more than two years ago, after testing positive for BRCA2—one of the so-called breast cancer genes—Manko voluntarily underwent a surgery few healthy women get: She had her breasts removed. She plans to do away with her healthy ovaries, too.

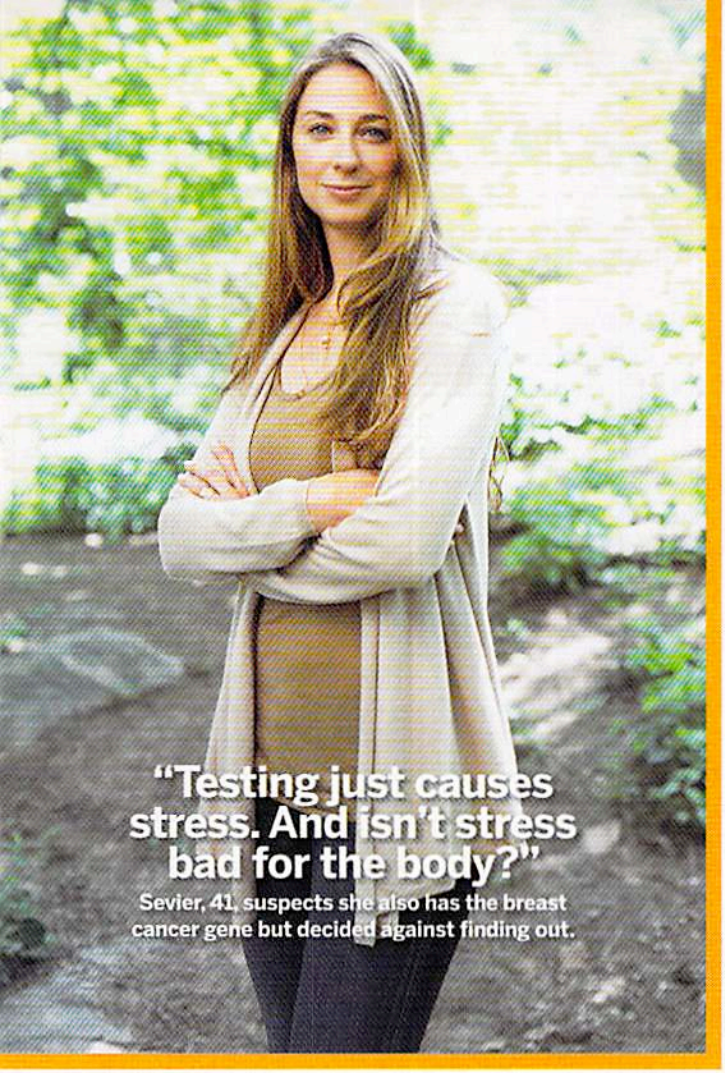
"It made perfect sense to me," Manko insists, curled up on the couch of her suburban Philadelphia home. Under her black sweater is a new pair of silicone breasts. Over the years, she has seen three family members, including her mother, diagnosed with breast cancer before they turned 45. "I wasn't gonna sit around and wait for cancer to get me," she says in a loud, cheerful voice. "The whole experience was empowering."

Her first cousin, 41-year-old Danielle Sevier, sees things very differently: Although she suspects she also has the breast cancer gene, she has vowed never to get tested.

"What's the point of knowing? So you can have the daylights scared out of you?" Sevier gently asks over lunch in New York City, where she lives. Because having the gene doesn't mean you'll definitely get breast cancer—one in five women with the gene is spared the disease—Sevier thinks the test would bring her nothing but unnecessary worry. And she has a word for her cousin's double mastectomy: mutilation. "Listen, if you *have* cancer, and you're trying to save your life, it's a different story," Sevier says, flicking her long, honey-colored hair over one shoulder. "But to do it without being sick, and in your 30s?" She chews her salad a moment. "Marni made her decision. And it's what's right for her, and I understand that."

Back in Pennsylvania, Manko is not nearly as diplomatic about her cousin's decision. "Danielle's crazy," she exclaims, laughing. "She thinks I'm nuts, and I think she's nuts!"

By Sabrina Rubin Erdely Photographs by Daniela Stallinger



"Testing just causes stress. And isn't stress bad for the body?"

Sevier, 41, suspects she also has the breast cancer gene but decided against finding out.

How much information is too much? With a vial of your blood, genetic testing can now reveal your likelihood of inheriting conditions such as schizophrenia, gastrointestinal cancer and Huntington's, the fatal degenerative brain disease. Alzheimer's and Parkinson's genes recently were discovered, and studies are honing in on genes for heart disease, autism and osteoporosis. Someday, this furious gene mapping may lead to cures. But for now, the diseases can't necessarily be prevented. What's more, testing can often only predict that you *might* get a disease—not that you *will* get it. Which means that patients who test positive for genetic mutations are sometimes left with more questions than answers, says Mary Daly, M.D., director of the Family Risk Assessment Program at the Fox Chase Cancer Center in Philadelphia. "It can change your whole attitude about your life, your future," says Dr. Daly, whose facility has counseled thousands of families. "Once you know that information, you can never go back to not knowing." The psychological jolt of such knowledge is enormous; a 1997 study at the University of Utah in Salt Lake City found that upon being told they carried the breast cancer gene, women were as stressed as people in another study who learned they actually had cancer.

Don't make your decision alone

BRCA testing is recommended for women who have...

- A mother, sister or daughter who had a diagnosis of breast cancer before age 50 or who had cancer in both breasts at any age
- Ovarian cancer in their family
- Relatives who have tested positive for BRCA1 or BRCA2
- Ashkenazi Jewish heritage along with a family history of breast or ovarian cancer

If you are at risk, talking with a genetic counselor can help guide you through your options. Visit the National Society of Genetic Counselors at NSGC.org.

Paradoxically, though, discovering you have a defective gene might provide peace of mind in the long term, says Andrew Baum, Ph.D., a researcher at the University of Pittsburgh Cancer Institute who recently studied the reactions of women considering BRCA (commonly pronounced "braca") testing. "By the end of one year, the only people whose distress level didn't go down significantly were the people who decided not to get tested at all," Baum says. "Whether the results are positive or negative, testing can reduce the uncertainty, and that reduces stress."

Genetic testing for breast cancer presents a particularly sticky dilemma. The two known genes, BRCA1 and BRCA2, account for only 5 to 10 percent of all breast cancers, which means that a negative result has little bearing on whether you'll someday get the disease. For that reason, the test is recommended solely for women who are most likely to be BRCA-positive (see "Don't Make Your Decision Alone," below). Despite the test's limitations, 1,500 women take it each week, according to its manufacturer, Myriad Genetic Laboratories in Salt Lake City, up from 700 tests per week in 2005.

A positive result packs a punch: It means you have as much as an 80 percent chance of getting breast cancer in your lifetime—most likely before menopause—and up to a 50 percent chance of ovarian cancer, with the BRCA1 gene carrying the higher risk. (Compare that with the average woman's lifetime risk of 11 to 12 percent for breast cancer and 1.4 percent for ovarian.) Those stats are scary enough to have created a whole new class of high-risk patient: the "previvor."

"It means 'survivor of a predisposition,'" explains Sue Friedman, founder of Facing Our Risk of Cancer Empowered in Tampa, Florida, a national support and advocacy group for people with hereditary risk. More than half of new visitors to FacingOurRisk.org, which gets 1.5 million hits monthly, are women under 45. The group is hoping "previvor" catches on, as the current term for a healthy person who tests positive for a genetic ailment is "unaffected carrier." Says Friedman: "Try telling a woman who's had her breasts removed that she's unaffected. Try telling that to someone who is going through menopause at 35 because she had her ovaries removed."

Manko recalls smiling as she walked into the genetic counselor's office one February day four years ago. "Just tell me I've got the gene," she urged. She'd given her blood two months earlier and was back at Fox Chase Cancer Center for the results. She was impatient for her gut feeling to be confirmed; she imagined it would be a relief.

The counselor nodded. "You do."

Manko bit her lip. "I knew it," she murmured, as her *(continued on page 208)*

STYLING, STACEY MAYESH. MANKO: HAIR AND MAKEUP, DEANNA MELLUSO FOR BECCA COSMETICS; PROP STYLING, ANGIE ARNETT. SEVIER: DEANNA MELLUSO FOR KANEBO COSMETICS.

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(continued from page 207) fiancé, Glenn, squeezed her hand. She'd been preparing for this moment, it seemed, her entire life. So she surprised herself when she immediately burst into tears.

Manko was in the eighth grade when her mother, Maxine, was diagnosed with breast cancer at age 43. Despite Maxine's double mastectomy, the cancer reappeared every few years, only to be beaten back by chemo or radiation. "My family lived in denial, in the sense that my mother didn't accept that she had cancer, so neither did we," says Manko, editor of the regional magazines *Bucks* and *Mainline*. That changed in 1998 when Maxine, a divorcée, called her 27-year-old daughter to report that the cancer had spread to her lungs. For the next four years, Manko saw her mother through her grueling decline, as the cancer spread to her liver and finally her brain. When Maxine died in 2002 at age 60, her daughter was at her bedside.

Manko resolved then and there to do everything in her power to avoid her mother's fate. She signed up for gene testing without hesitation. "I know my mother wouldn't have approved. That's not the way she lived," she says. "But I'm a control freak. I needed to know."

The first step had been to sit down with a genetic counselor, who explained the test's shortcomings. Its accuracy is not a given; a study published in 2006 in *The Journal of the American Medical Association* found that 12 percent of breast cancer patients who had the BRCA1 or 2 gene nevertheless tested negative. Manko's counselor had also discussed the shock of testing positive, which can trigger depression or anxiety. The test's price tag is also considerable: $3,120, and insurance doesn't always cover it. (Manko's costs were low because she was tested as part of a study.) Lastly, her counselor had laid out Manko's cancer-prevention options.

Now, having tested positive for BRCA2, Manko needed to consider those alternatives seriously. The first option was to keep a close eye on her through frequent mammograms and magnetic resonance imaging—but that wasn't proactive enough to suit her. The second option was to take the drug tamoxifen, which may reduce breast cancer rates by nearly half in high-risk women (but which only 12 percent of American BRCA-positive women take preventatively, for fear of its side effects). Manko ruled that out, too, partly because she was hoping to get pregnant and the drug can harm a fetus. That left door number three: surgery.

It's an option many women are taking. A survey of 2,000 BRCA-positive women worldwide found that 33 percent of healthy American women chose preventive mastectomies and 71 percent had their ovaries taken out, says lead researcher Steven Narod, M.D., director of the Familial Breast Cancer Research Unit at the Center for Research on Women's Health in Toronto. Dr. Narod would like to see still more mastectomies. "If we're going to prevent cancer in BRCA carriers, we need to intervene and to do it early," he says. "In our program, we begin discussing prophylactic mastectomy at age 25. We recommend preventive oophorectomy fairly strongly at 35. By 40, it's often too late."

As it stood, Manko had an 80 percent chance of having breast cancer. A double mastectomy, which would remove her breast tissue, cut the risk to about 5 percent. "Drastic!" she says. "When I heard that, I was like, How can I *not* do this?"

Even so, Manko deliberated for months. Although Glenn was her biggest cheerleader—once volunteering "You'll need new nipples? You can have mine!"—she worried how he'd react. Finally, she went to the home of a family friend, a surgeon. "I'm going to talk to you as a friend, not as a doctor," he told her. "My mother died at 32 of breast cancer. I never got a chance to know her." He looked her in the eye. "Do it."

Manko was flooded with the relief she'd long been hoping for; finally, she felt ownership of her situation. But the plan would have to wait: Manko was pregnant. Even as she admired the shape of her swelling breasts, she was already disassociating herself from them. She avoided looking at herself naked and told Glenn, who was by now her husband, to keep away from her breasts in the bedroom. "I began to kind of hate them," she recalls. "I knew one day I was going to wake up and they were gonna be gone, and if I was emotionally attached, it would make it really hard."

When in March 2004 Manko gave birth to her daughter Mackenzie—nicknamed Max, after Manko's mother—she found herself unable to breast-feed. "She wasn't latching on, but it was more me. I didn't want to get close to my boobs," she says. Having a child redoubled her urgency to have surgery. The idea of putting Max through what she had endured with her own mother was unthinkable.

So it was with great impatience that in December 2004, Manko stood in the pre-op room, stripped to the waist, as surgeons drew on her with green Magic Marker. She didn't look down to bid her breasts good-bye; she had written them off long ago. *Good riddance.*

"I've cried over Marni," her cousin Danielle Sevier says, stabbing unhappily at her salad. "I think it's absolutely horrendous. It makes me sick; it makes me sad." Whereas Manko had been sure she'd someday be stricken, "I've always believed I'm *not* going to get cancer," says the soft-spoken Sevier, a real estate agent. Her optimism comes despite a family history riddled with the stuff. Her mother—Maxine's sister—was diagnosed in her early 40s, when Sevier was only 21. As with Manko, the job of supervising treatment fell to Sevier. She drove from Connecticut to New Jersey every two weeks to sit with her mother through wrenching chemo sessions. "It was a hard, miserable year, and it definitely affected me in a strong way," she says. Fortunately, the cancer went into remission. Then Sevier's father died after a prolonged battle with colon cancer. In 1998, her sister, Randy, tested positive for BRCA1 and had a prophylactic oophorectomy; she was diagnosed with breast cancer two years later at age 37, eschewing a lumpectomy in favor of a double mastectomy. And of course, there was Aunt Maxine.

Given her history, Sevier thinks she may indeed have the breast cancer gene. But that doesn't mean she's about to find out. "I could have the gene and not get cancer. Or not have the gene and get cancer anyway," she reasons. "I don't see what good it serves. It just causes stress. And isn't stress bad for the body?"

Sevier knows her cousin did what she felt she had to after the loss of her mother. Still, she is shocked by the way Manko made such a dramatic decision based on what Sevier feels is inconclusive evidence; having BRCA2, she points out, doesn't definitively mean Manko would get cancer. Because breast-feeding for one year or more can reduce a person's risk for breast and ovarian cancers, Sevier, who nursed her own daughter, feels that when Manko denied herself the chance to breast-feed, she took a major weapon out of her cancer arsenal. Sevier wonders whether, because today's breast-reconstruction techniques are so good, women submit to surgery far more casually, deciding too quickly that their breasts aren't essential.

"My breasts are not ornamental," Sevier says heatedly. "My breasts give me a lot of pleasure: how I look in clothes, how I feel about myself. And I mean, my husband—not to get overly sexual here, but—they're very stimulating, and exciting and fun! And to take away something that should, if women allow it, give them pleasure, is just..." she breaks off, shaking her head. In her heart of hearts, Sevier suspects that this whole lop-off-your-healthy-breasts-and-ovaries movement is actually a form of oppression: It's male doctors and researchers, by and large, advising women to alter their sexuality "in ways they would never do themselves," she asserts. "If we didn't live in such a male-dominated society, there would be other options not involving mutilation."

But more than anything, Manko's surgery, and the BRCA test in general, goes against Sevier's instinct that it won't help in the long run; that when it's your time, it's your time, and there's no sense obsessing over what could be when you can simply appreciate the present. "Quality of life, to me, is way more important than quantity," she explains. "I'll enjoy myself while I'm here and not worry about things that aren't within my control." That she's married and has an 11-year-old daughter does little to change her mind. When it comes to prevention, Sevier simply tries to lead a low-stress life, exercises and takes herbal supplements that purport to bolster the immune system, such as cow colostrum capsules *(continued on page 210)*

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(continued from page 209) and maitake mushroom-extract drops. (In studies, both have shown some immune-boosting benefits; Memorial Sloan-Kettering Cancer Center in New York City has a breast cancer study under way to put maitakes' cancer-fighting powers to the test.)

In October 2005, during Breast Cancer Awareness Month, Sevier's husband, Donald, made it clear that he wanted her to ratchet up her prevention efforts. He knew her well enough to take a lighthearted approach; each morning when they awoke, he'd smile and ask, "Do you know what month this is?" Once he had his wife chuckling—or at least rolling her eyes—Donald would go a step further: "I want you here. You have to take care of yourself." He left it at that. Sevier now sees a specialist every three months for a rotating schedule of mammograms, sonograms and MRIs—ironically, similar to monitoring she'd get if she tested positive for BRCA. "But I won't let it take over my life. Not like Marni," Sevier says. "It's a shame. She had beautiful breasts."

Two weeks after Manko was released from the hospital, her extended family converged on her aunt's house in Woodstock, New York, to spend some quality time together. Manko had awoken from surgery with a set of expanders embedded in her chest, half-moons of saline that would slowly and painfully stretch the muscles until they could accommodate her implants. Her chest was threaded with red scars, but she was so delighted to have surgery over with—and pleasantly fogged with Valium—that she couldn't stop herself: Sitting at the kitchen table, Manko lifted her shirt and flashed her cousin.

"What do you think?" Manko asked.

Sevier kept a straight face. "Looks good," she said, but Manko saw apprehension in her eyes. Not that it made a difference; she was, and is, satisfied with her choice. "I feel like, Screw you, cancer! You took my mom. You're not gonna take me," Manko says, her mouth curved in a smile but her eyes flashing. "And it feels great. I don't worry about it anymore. Because now I know I won't get it."

It took five months of expanders and multiple surgeries before Manko got her new breasts: a pair of C-cups a smidge larger and perkier than her original pair. "I figured I might as well have fun with it," she says with a laugh. She is pleased with the results and has proudly worn a bikini. Still, she sometimes feels a twinge when she sees herself naked or watches a nude scene and remembers what real breasts look like. Though realistic-looking beneath her clothes, hers are artificially spongy and round, numb to all feeling and capped with tattooed-on areolas.

Last July, Manko gave birth to her second child, a girl she and Glenn named Sydney. She is allowing herself only a temporary break from surgery; in a few years, she wants her ovaries removed. Her decision to get an oophorectomy has been a tough call, because she has no family history of ovarian cancer and BRCA2 women like her are less likely to get it than those with BRCA1. Plus, an oophorectomy brings instant menopause, with its heightened risks of osteoporosis and heart disease, to say nothing of hot flashes and low sex drive.

There are less dramatic alternatives to minimize the risk for ovarian cancer, such as having one's tubes tied, which research has found can reduce risk in BRCA1 women by about 60 percent. But for Manko, the oophorectomy numbers are too compelling to resist: Having surgery will cut her risk for ovarian cancer from a high of 30 percent down to 5 percent. (The risk is never zero because cancer can still develop in the cells that surrounded the ovaries.) An oophorectomy will also minimize Manko's already small threat of breast cancer, as having the ovaries out (thus shutting down most estrogen production) reduces breast cancer risk by half. "I don't ever want to look back and think, I could have done more," Manko says.

Although the cousins remain mystified by each other's actions, Manko wonders whether perhaps both women are equally defiant in the face of cancer but are simply acting in keeping with their personalities. Type A Manko is intent on beating cancer by outsmarting it, and holistic Sevier is just as audacious in standing her ground, not conceding an inch. "I think Danielle is like, Why am I gonna cut my breasts off? Because of *cancer*? No way!" Manko says. "It's a lifelong battle for both of us. It just manifests in different ways." ■

SELF CHALLENGE CONTEST RULES

NO PURCHASE NECESSARY. A purchase will not improve your chance of winning. Promotion begins January 23, 2007, at 12:01 A.M. ET, and ends June 14, 2007, at 11:59 P.M. ET ("Promotional Period"). To enter, log on to Self.com, follow the link to the SELF Challenge and complete the registration process. You may register for the SELF Challenge only once. Employees of The Condé Nast Publications and Condé Net Inc. ("Sponsors") and their immediate families are not eligible.

GRAND PRIZE SWEEPSTAKES All eligible participants who register for the SELF Challenge during the Promotional Period will be entered into the drawing for the Grand Prize Sweepstakes. One potential winner will be chosen in a random drawing on or about June 21, 2007. Winner will be notified by phone, mail or e-mail. Winner will receive a trip for two to Paris, France. The prize package includes two round-trip coach airline tickets from the major commercial airport nearest the winner's home in the United States to Paris; ground transportation between the airport and the hotel; accommodations for two nights (double occupancy) at a hotel chosen by Sponsors; a per diem not to exceed $150 per day per person (for a total of $300 per day) for three days toward meal expenses at restaurants of winner's choice; a selection of face and body treatments for the winner and her guest at Clarins Institut selected by Sponsors (not to exceed $500 each for a total of $1,000) and two gift bags of Clarins products selected by Sponsors ($500 each for a total of $1,000). Additional spa/sports, health/healing or optional services, local and long-distance telephone charges, in-room charges (e.g., minibar, movies), gratuities, incidentals, store purchases, workshops or consultations, lessons, off-property outings and all ground transportation other than to and from the airport are not included. Incidentals and all other expenses are to be paid in full at time of checkout by the winner. Restrictions and blackout dates may apply. Subject to availability. Trip must be completed by August 1, 2008. Prize holds no cash value and cannot be combined with any other special offer or promotion. Travel companion must be 18 years old or older. Approximate retail value (ARV) of the prize is $5,450, depending on actual itinerary. Winner and guest must travel together on the same itinerary.

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FINISHERS' GIVEAWAY All eligible participants who have submitted all three SELF Challenge monthly workout logs by 11:59 P.M. ET on September 14, 2007, will automatically receive a gift card worth at least two free song downloads, courtesy of Asics (ARV $2). Prize must be redeemed by September 15, 2008. Prize holds no cash value and cannot be combined with any other special offer or promotion.

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