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A MOTHER'S CHOICE: KELLY KLITENICK, WITH HER DAUGHTER, LAUREN, AFTER THE REMOVAL OF BOTH HEALTHY BREASTS.

drastic measures

Are breasts essential to feeling feminine? Not when you're plagued by a deep fear of cancer, discovers Margit Bisztray.

Four times a week, my friend Kelly Klitenick and I work out in her home gym. We exercise barefoot, away from crowds, while our baby daughters toddle by and our sons play spy under the carob tree. Kelly used to be a personal trainer, and she never fails to take us through a strenuous routine. We exchange stories about the day's events—the gala fund-raiser she and her husband, Richard, attended; the story I've been pursuing for the paper.

One afternoon, during a set of lunges, Kelly announced that she had scheduled a mastectomy for both her healthy breasts. I didn't know what to say. Kelly is 33 years old and stands out in a crowd. She is six feet tall, blonde, with olive skin, long legs, and great taste in clothes. She cares about her appearance. She is not a compulsive worrier or a hypochondriac. Her decision to eliminate her breasts seemed completely out of character.

But to Kelly, it made perfect sense: She is a prime candidate for breast cancer. Her maternal grandmother and mother were both diagnosed with the disease before menopause, she told me. She gave birth to her children at an older age than they did, and that puts her even more at risk. She informed me that for the average woman, the chance of breast cancer during her lifetime was 12 percent; but for her, it was significantly higher, up to 50 to 80 percent. Her fear of cancer was complex and unrelenting, she explained, as was her motivation to stay alive for her family. Besides, she said, shrugging, "I'm not defined by my breasts."

But are we? Breasts—milk glands surrounded by fat and suspended by connective fibers—are indeed appendages and, from a practical perspective, dispensable appendages at that, especially for women with no need, or no desire, to breast-feed. As Natalie Angier argues in *Woman,* breasts are "pretty, they're flamboyant, they're irresistible. But they are arbitrary, and they signify much less than we think." And yet if that were true, then all high-risk women would eagerly zero in on the cause of their medical problem, as one would a time-release bomb. The reality is that even among women with the BRCA-gene mutations—defects that put women at highest risk—less than a third choose to have a prophylactic mastectomy.

The breast is different from other parts of the body. It is gender-specific, and therefore sexual and political. We may be aware that what we love is actually what Angier calls the "fantasy" of the breast, not the functionality of it, but that doesn't stop us from making medical decisions based on our irrational love. And so, when one comes across a woman like Kelly, who went about her decision as if it were a simple cost/benefit matter, it's astonishing.

Most women first heard about prophylactic mastectomies back in 1999, when a Mayo Clinic report in the *New England Journal of Medicine* compared the survival rates of 214 high-risk women who had undergone the surgery with those of their sisters who had not. The procedure reduced the risk by 94 percent. The same Mayo Clinic team later focused on a more specific population: those with the BRCA1 and BRCA2 mutations. According to their findings, published this past year in the *Journal of the National Cancer Institute,* these women reduced their susceptibility by 89.5 percent at an average of 13.4 years after the surgery. Some estimates pushed the figure as high as 100 percent.

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KEVIN STURMAN; hair and makeup, Shoukoufeh Azari for ARTISTS by Timothy Priano.

Unlike the case with the initial report three years ago, the response following the latter study was subdued. The shock value seemed to have diminished, especially since very few women who had undergone the surgery wanted to speak about it on the record. It was a private matter, and the absence of headlines muted the discussion. Besides, there are easier preventive strategies on which to focus: quitting smoking, eating less fat and more fruits and vegetables, and exercising three to five times a week. After age 40, there is mammography, which isn't infallible, though it does reduce the risk of breast cancer death by 30 percent. It seemed the closest thing we had to a foolproof prevention strategy.

Her mother wasn't convinced. "How can you butcher yourself?" she asked. "Even cancer patients try to preserve their breasts"

But then, this past October, a Danish study shook that confidence. Researchers at the Nordic Cochrane Center in Copenhagen reported in *The Lancet* that early detection made little difference in cutting the risk of dying of breast cancer. Their argument was bolstered by another statement issued in January by an independent expert panel. Known as the P.D.Q. (Physician Data Query) screening and prevention editorial board for the National Cancer Institute Web site, this group also concluded that the studies supporting annual mammograms were flawed. While experts maintain that women should continue their screening regimen, it's hard not to wonder, What else can we do?

Kelly was asking this question long before the news broke. She never trusted mammograms—they missed her mother's lump. Screening has always been questionable for women under age 40 anyway, since their breast tissue is dense like oatmeal, making tumors hard to detect. She didn't want to take a chance. "It wasn't just that I didn't want to die," she explained. "I didn't want to be sick. I saw my mother go through the nausea and lack of energy during chemotherapy. I didn't want to be too weak to spend time with my daughter and son. Then I saw that 94 percent," she said referring to the *NEJM* article, "and I knew."

When she told Richard about the mastectomy, it frightened him. The two decided to discuss the matter with breast specialists and plastic surgeons. One cautioned that the procedure was "mutilating." He explained that breast tissue is larger than we think: It extends from the collarbone to below the rib cage, and from the breastbone around toward the back. This breadth, along with the fact that breast tissue looks very similar to any other tissue, makes it impossible to remove fully. A skillful surgeon is able to take away 98 percent, but some breast cells always remain behind.

In other words, as Chicago breast specialist Valerie Staradub, M.D., later explained to me, mastectomies "will never decrease the [cancer] risk to zero." That is why Patrick Borgen, M.D., chief of breast surgery at Memorial Sloan-Kettering, prefers to call the procedure a "risk-reducing" rather than a "prophylactic" mastectomy. "It looks like it works," he cautioned, "but it's not perfect, and it's a huge price to pay. Nobody wants to build the future of breast cancer prevention on Draconian surgery, especially when there are drugs being tested that may be equally good preventive agents." Doctors cite a litany of risks, including infections, future screening difficulties (mammograms become impossible once breasts are removed), emotional trauma, and even a false sense of security. Complication rates can be as high as 30 percent for women who undergo the surgery.

Still, Kelly persisted. Tamoxifen, sometimes used as a preventive drug, is not a surefire solution, and the data on other drugs being tested, such as Raloxifine, which has been used to treat osteoporosis, won't be available for three to five years. Undeterred by the risks, she fixated on the promise of living without fear.

Kelly's plastic surgeon suggested she talk to other women who'd had the same procedure. She agreed but heard only the answers she wanted to hear and didn't push past them. "The two I talked to were middle-aged," she reported. "They said they felt great. They said their husbands were supportive." She never did ask what their breasts looked like afterward. She said she didn't care; or perhaps she just didn't want to know. Instead, she kept insisting her breasts were appendages. "It's not going to bother me," she told herself and others.

Her mother wasn't convinced. "How can you butcher yourself?" she asked. "Even cancer patients try to preserve their breasts." She begged Kelly to wait, to do more research, to see what science would turn up in the near future. "Why are you rushing this?" she demanded angrily.

Kelly didn't tell her mother the day she checked in for surgery last May. "I was acting for my children, not for my mother," she said. She and Richard knew many of the doctors personally, and they offered their support before she was wheeled into the operating room; they made her feel at home. She wasn't anxious, she told me, for she had had other kinds of surgery before. "I was just relieved to be getting it done," she explained.

The process took about three hours and consisted of two parts. The first, and simplest, was the actual removal of the breast. Her surgeon cut an ellipse in the chest area, removing both skin and tissue, from collarbone down to pectoral muscle.

If the woman has breast-reconstruction surgery, as Kelly did, a plastic surgeon then takes over. Because there is essentially no breast tissue left, the augmentation procedure is more complicated than in an aesthetic-surgery situation. The cup size must be increased gradually, or else the tissue might go into shock, so the doctor uses tissue expanders as opposed to fully inflated implants. (Replacing the breast tissue with excess skin from elsewhere would have been another option.) Valves placed just below each armpit allow the surgeon to inject saline solution into the expanders over the next several weeks. The skin is sewn shut using a double set of stitches, one internal, one external, forming a seam neat as teeth. Nipples and areolae (constructed out of tissue from the patient's thigh) create an almost natural appearance.

When Kelly awoke from the general anesthesia, she felt a heavy, burning pressure, as if she had hot cinder blocks on her breasts. "I felt like I had smashed into the steering wheel during a car accident," she said. She spent one night in the hospital, then returned home. A few days later, bruising set in, causing aches and pain that lasted all month. "I couldn't move *health* ▸*210*

my arms for two weeks," she said. "I couldn't hug my kids, and that was hard for them to understand. I couldn't even bathe myself; I needed Richard's help. I'd try to pick things up and do housework and cook, but I eventually gave up."

The hardest part turned out to be the appearance of her postoperative breasts, and this is typical. Explains New York City psychologist Alison Ross, Ph.D., "The loss of any body part is traumatic, but this part is particularly emotionally laden. It needs to be clear that while this may be a logical decision, it will have huge emotional implications." That's why experts sometimes refer patients for presurgical psychological counseling.

Kelly skipped that advice. It was not surprising, then, that she was astonished the first time she stood sideways after her operation, the way girls do when they are twelve and searching for curves. This was shocking for Kelly, a woman who once had no qualms about going topless on South Beach. "I must admit, it doesn't feel sexy to be naked anymore," she confessed with a trace of wistfulness in her voice, but not much. "I'll never go naked in public now, like at the spa or a gym, but mostly because I don't want people to feel sorry for me."

Her family has been generally supportive ("You look great," her husband frequently tells her), but few will speak of the surgery in depth. "I think they're too stunned," she says. "People I don't know as well see the practical side. They have an easier time accepting what I did." Kelly herself has felt relief and celebration.

The recovery process will inch life back toward normal, though not yet. Each week, Kelly continues to watch her breasts expand like pool toys. After an injection, she feels a taut pulling sensation that starts below her neckline and tapers into numbness somewhere in front of her. No nerve endings remain, so what used to be her sensitive nipple points feel as if they were on Novocain. "Orbs," she calls her breasts-in-progress, squeezing them although she can't feel the squeeze. Even in South Florida, where augmentations are common, Kelly can't help wondering: Can people tell? Do they look real enough? Do I look normal?

As weeks passed, complications ensued. The implant behind Kelly's left pectoral expanded, and then hardened and bulged. Her surgeon worried she would need to have the implant rebuilt, but fortunately, it has since softened to a natural density. At the same time, her insurance company, which had precertified coverage of both the mastectomy and the reconstruction, refused the claim, deeming the work "elective." With an attorney, Kelly reached a settlement covering the whole procedure, but the battle made an already arduous journey even more so.

No nerve endings remain, so what used to feel sensitive now feels as if it were on Novocain

Despite the obstacles, Kelly has no regrets. "All my life, I heard about how horribly Grandma died," she told me one night at a wine bar. "I heard about her body curled up in agony, about my grandfather giving her morphine and the needles in his dresser drawers. This was my mother's world between the ages of ten and fourteen. She always told me, 'I didn't have a mother, a nurturer.' And then she got sick, and I thought, That's it; I'm next. I couldn't put my kids through the kind of loss she described to me." She paused, sipping her Chardonnay. "The last few months after the surgery have been weird, but that's because I wasn't prepared. I would go through it again if I had to because at least now, I'm no longer afraid of getting breast cancer."

By late fall, we were back at the gym. Kelly asked if I'd consider making the choice she did. I told her no. I mourned the breast my mother lost to her single mastectomy eight years ago. Besides, having my breasts removed would not make me feel safer, only emptier. Risk and fear, I came to realize, are not necessarily related. Risk can be assessed, but fear is primeval. For some people, fear just can't be reasoned away.

Kelly simply nodded at my reply to her question and handed me a pair of weights, ordering fifteen chest presses. I started lifting and thought of the Amazons, strong women who sliced off their breasts to better carry their spears. □

DEFENSE MECHANISMS

Putting the mammography debate in perspective.

While the prevention of breast cancer requires more aggressive steps for those with a family history of the disease, the American Cancer Society's screening recommendation for low-risk women has remained virtually unchanged for two decades: monthly self-exams starting at age 20, and annual mammograms at 40 and after. But when a *Lancet* article cast doubt on the efficacy of mammograms last October, confusion ensued, with some experts finding them more beneficial for women closer to 50. Although several organizations, including the National Cancer Institute, reaffirmed the ACS protocol, the fact is, mammography has never been a perfect science. And so, along with ultrasounds and MRIs, new technology may soon work in tandem with conventional screening methods. "Women need to realize that an abnormality in a mammogram does not mean cancer in more than 80 percent of cases," explains Yuri Parisky, M.D., director of breast imaging at Norris Cancer Center at the University of Southern California. Here is what's available now and in the near future:

Thermal imaging: Pending FDA approval, this procedure identifies "hot spots" in breast tissue with a sensitive thermal camera—the theory being that cancerous tissue duplicates aggressively and therefore emits more energy than healthy tissue. As a result, it gives doctors information in addition to what they would find on a regular mammogram. **Chemoprevention:** Intended for women at high risk, several tumor-shrinking drugs, like Aromasin and Tamoxifen, are currently being examined in large-scale studies as a cancer-prevention method. **Ductal lavage:** By testing the fluid from the milk ducts (where approximately 95 percent of cancer begins), doctors can look for abnormal cells before sending a patient under the knife. The procedure is available now but is still hotly debated within the medical community. **Sestamibi scans:** Most hospitals currently offer this option, in which doctors inject a radioactive compound that accumulates only where the cancerous tumors hide, thus making them more visible in scans.—CAROLINE PALMER