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THE DNA AGE

Cancer Free at 33, but Weighing a Mastectomy



Sally Ryan for The New York Times

Deborah Lindner, 33, did intensive research as she considered having a preventive mastectomy after a DNA test.

By AMY HARMON
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CHICAGO — Her latest [mammogram](#) was clean. But Deborah Lindner, 33, was tired of constantly looking for the lump.

The DNA Age

Changing the Odds

Articles in this series explore the impact of new genetic technology on American life.

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Ever since a DNA test had revealed her unusually high chance of developing breast [cancer](#), Ms.

Lindner had agonized over whether to have a mastectomy, a procedure that would reduce her risk by 90 percent.

She had stared at herself in the mirror, imagining the loss of her familiar shape. She had wondered, unable to ask, how the man she had just started dating would feel about breasts that were surgically reconstructed, incapable of feeling his touch or nursing his children.

But she was sure that her own mother, who had had [chemotherapy](#) and a mastectomy after a bout with the cancer that had ravaged generations of her family, would agree it was necessary.

“It could be growing inside of me right now,” she told her mother on the phone in February, pacing in her living room here. “We could find it any time.”

What did Dr. Lindner's father say?

What did her sister say?

What did her aunt say?

What did her cousin do?

How many American women have the BRCA gene?

What are their chances of getting breast cancer/

What is the percentage of women with the BRCA gene get ovarian cancer?

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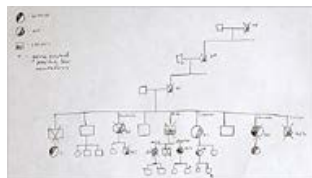
[Living with the BRCA Gene: One Family's Story](#)

ADVANTAGES	DISADVANTAGES
Shown to decrease mortality in the general population	May miss up to half of young women.
Much more sensitive than mammography in young women; detects 64-100% of breast cancer.	May give ambiguous results requiring 11% of women unnecessary exams or cancer.
Can detect some tumors that are missed by mammography.	Only detects 32-39% of high-risk women when used as a screening tool.

Graphic

[Weighing the Options](#)

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Sally Ryan for The New York Times

A Lindner family chart showing the path of breast and ovarian cancer in relatives, and those who had died.

[Enlarge This Image](#)

Waiting for an endorsement, she added, "I could schedule the surgery before the summer."

But no approval came.

"Oh, sweetheart," her mother said. "Let's not rush into this."

Joan Lindner, 63, is a cancer survivor. Her daughter, by contrast, is one of a growing number of young women who call themselves previvors because they have learned early that they are genetically prone to breast cancer, and have the chance to act before it strikes.

As they seek to avoid the potentially lethal consequences of a mutant gene, many of them turn to relatives who share its burden. But at a moment when a genetic test has made family ties even more tangible, they are often at their most strained.

Parents who have fought cancer typically have no experience with the choices that confront their children, and guilt over being the biological source of the problem can color their advice. Siblings and cousins who carry the risk gene evangelize their own approach to managing it, while those who dodged its inheritance seem unqualified to judge.

Even as she searched for her own answer in the year after her DNA test, Deborah Lindner, medical resident, found herself navigating her family's strong and divergent opinions on the imperfect options that lay before her.

Her father, who once feared he would lose his wife to cancer, encouraged the surgery. Her sister reminded her that cancer might be cured in a few years if she could wait.

Her aunt said she hated to see her niece embrace a course of action akin to "leechings of the Dark Ages." A cousin declined even to take the DNA test.

But it was her mother's blessing that Deborah most eagerly sought.

Mrs. Lindner, who had passed her defective gene to her daughter, wanted to will her more time. When she had her own breasts removed she had been married for 27 years and had raised two daughters. Now Mrs. Lindner couldn't shake the fear that her daughter might trade too much in her quest for a cancer-free future. What if taking such a radical step made it harder for Deborah to find someone special and become a mother herself?

"I have this amazing gift of knowing my risk," her daughter told her over the phone that winter night, gazing out over the frozen city from her apartment on the 38th floor. "How can I not do anything about that?"



Sally Ryan for The New York Times

Deborah Lindner jogging along Lake Michigan in Chicago the day before undergoing a double mastectomy.

[Enlarge This Image](#)



Sally Ryan for The New York Times

Ms. Lindner and her mother, Joan Lindner, getting pedicures the night before the preventive surgery.

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Sally Ryan for The New York Times

Ms. Lindner with her boyfriend, Jeff Zehr, after the surgery at Evanston Northwestern hospital.

The Lindners share a defective copy of a gene known as BRCA1 (for breast cancer gene 1) that raises their risk of developing breast cancer sometime in their lives to between 60 and 90 percent. Only 30,000 of more than 250,000 American women estimated to carry a mutation in BRCA1 or a related gene, BRCA2, have so far been tested. But their numbers have doubled in the last two years, and with a sharp increase in genetic testing, are expected to double again in the coming one.

About a third opt for preventive mastectomies that remove the tissue where the breast cancer develops. A majority have their ovaries removed, halving their breast cancer odds while decreasing the risk of highly lethal [ovarian cancer](#), to which they are also prone. Some take drugs that ward off breast cancer. Others hope that frequent checkups will catch the cancer early, or that they will beat the odds.

Their decisions, which require weighing an inborn risk against other life priorities, are highly individual. But with DNA forecasts of many other conditions on their way, BRCA carriers offer the first clues for how to reckon with a serious disease that may never arise — and with the family turmoil that nearly always does.

A 50-50 Chance

Deborah Lindner's sister, Lori French, got her results first.

Long ago, before she knew about the DNA test, Ms. French, 37, had resolved to have her breasts and ovaries removed by age 40 to avoid the family cancer. Nor did she want reconstructive surgery, having seen her mother struggle with the pain and cosmetic disappointment of hers.

"Plan on it," she had told her husband before they got married a decade earlier. "I'm going to get old and have

big hips and no breasts."

The envelope with the test results that Ms. French opened with shaking hands in the summer of 2005 offered a reprieve. She and her husband sobbed, hugging each other in the knowledge that she was free of the genetic defect. While she still had the 12 percent chance any woman has of developing breast cancer, she could not have passed on the steep BRCA risk to either her daughter or son.

"It's done!" Ms. French told her family. "In our line, it's ended."

For years, the sisters had united in a common dread. Now it was Deborah's alone.

"I'm so sorry you have to be the one," Ms. French said when her sister called a week later with the news that she had tested positive for the mutation.

"I'm so glad it's not you," Deborah replied.

It could have been either, neither or both of them — each sister, she knew, had had a 50 percent chance of inheriting the defective gene from their mother, dictated solely by a roll of the genetic dice. But if it was going to be one of them, Deborah thought she was in a better position to handle it. Her sister taught at a missionary school in the Philippines, where she lived with her family, while Deborah was single and in the second year of her medical residency program at Northwestern University, with ready access to quality health care.

Yet in the weeks that followed, Deborah fought off pangs of jealousy and the fantasy that fate could somehow be rearranged.

“She already has a husband, she already has kids,” Deborah thought on morning runs along Lake Michigan.

She enrolled in a stepped-up surveillance program that required alternating mammograms and sonograms with [M.R.I.’s](#) every six months. But on the mornings of her appointments, and at unpredictable moments in between, she was overwhelmed with fear. Often, she would examine her breasts every other day.

“It’s taking over my mind,” she told Erin King, a close friend and fellow resident in the obstetrics and gynecology program.

Ms. King, 33, who had had breast implants for cosmetic reasons, and another resident friend were proponents of pre-emptive surgery.

“Get them off and get new ones,” they told her. “They’ll be awesome and perky and cute.”

But they sympathized with her distress at the appearance of traditional reconstruction, with skin grafts molded into a fake nipple that can never quite match the texture of a real one and the areola simulated by a tattoo.

“They just don’t look normal,” Deborah sighed as they debated the question over the barbecue grill at Ms. King’s apartment one night.

Accustomed to seeking her mother’s counsel, Deborah kept her distance in those months, not wanting to worry her. Instead, she pestered breast specialists. How many cancers do you actually catch? How many in an early stage? The answers were vague. Still, they discouraged her from surgery. Most women who had a preventive mastectomy, a breast surgeon told her, already had a family.

A Frightening Pattern

In the fall of 2006, Deborah turned her residency research requirement into a personal quest for better information, analyzing the records of BRCA mutation carriers who had been counseled at Northwestern.

One file told of a woman who had developed cancer and chosen a lumpectomy, a procedure that leaves the breast mostly intact. The cancer came back — while she was pregnant. When she had an early [Caesarean section](#) so she could get chemotherapy without harming the baby, doctors discovered an ovarian [tumor](#) that had already spread to her abdomen.

The pattern was not uncommon. BRCA-related breast cancer usually strikes early, before age 50, and is more likely to recur in the other breast. Ovarian cancer, which strikes about 50 percent of BRCA1 carriers, compared with 2 percent of the general population, is rarely detected early and is fatal three-quarters of the time.

“It’s like I’m reading this book and I know what’s coming,” Deborah told her fellow

residents. "I see the note, 'Patient opts for surveillance,' and I'm like, 'No, don't do it, don't do it!'"

Several times during her oncology rotation that term, she slipped out of an ovarian cancer patient's room to cry in the stairwell. To eliminate her risk of ovarian cancer, doctors had recommended that she have her own ovaries removed by age 40, or as soon as she had children. Removing her ovaries would halve her breast cancer risk as well, but the hormones that are generally used to treat the harsh menopausal symptoms brought on by the procedure, Deborah learned, would then raise the risk again — unless she had her breasts removed first.

Unspoken Questions

Over Thanksgiving at her parents' winter home in Florida, Deborah ran through her risk analysis. Her father, Philip Lindner, listened and nodded. Mammograms and ultrasounds, she noted, may miss more than half of cancers in younger women with denser breasts. Magnetic resonance imaging tests are more reliable but produce more false positives, which can lead to unnecessary biopsies and worry. And it is not yet clear that early detection improves survival rates in women with BRCA mutations.

"You can't argue with statistics," said Mr. Lindner, a financial executive. "You don't want to get cancer and then say, 'I wish I would have done thus and so.'"

Deborah's mother agreed it was important to know the risks. But not knowing them could be a luxury, too. Had she had the same options as her daughter, would she have found a man and had a family? It might have altered her whole life.

"I know the joy that my girls have brought to me," she confided to a friend. "If Deb misses it, she won't know what she missed. But having experienced it, I would never have wanted to miss it."

Tentatively, she broached the subject of breast-feeding with her daughter. "That was something very special to me," Mrs. Lindner said.

"Wouldn't it be more special," Deborah shot back with uncharacteristic edge, "if I was around to have children in the first place?"

But if her mother worried that surgery would make her less attractive to men, Deborah shared those concerns.

"Do fake boobs freak you out?" she often imagined asking Jeff Zehr, the man she had begun dating a few months before.

Mr. Zehr, a fellow marathon runner who attended her church, had told her she was special to him, and she felt similarly. But she didn't want to scare him away or, worse, put pressure on the relationship to proceed faster than it otherwise would.

As Deborah felt increasingly torn between life events that couldn't be rushed, and surgeries that shouldn't wait, there was one more piece of information she thought would sway her mother.

"Will you do something for me?" she asked. "Look through the family tree and find out how old everyone was when they got their cancer."

The answers were chilling. One of her first cousins, Mrs. Lindner learned, had breast cancer at age 33. Now the cancer had returned, and she was losing the fight.

Another first cousin got her breast cancer diagnosis at 34; she died. Her daughter, at 33, had recently learned she had the disease.

Mrs. Lindner called her daughter. "Have the surgery as soon as possible," she said.

But a few days later, Mrs. Lindner called back. Her mother's ovarian cancer, she remembered, had not surfaced until she was in her 70s — and she had survived. Joan Lindner had been 48 when the doctors detected her breast cancer, and she had survived too.

"We were really on the far side of the bell curve," she said.

Memories of Chemotherapy

Deborah remembered her mother's cancer diagnosis, which came just before her graduation from high school. Her school choir had been selected to sing at Carnegie Hall, and her parents had planned to come as chaperones. Instead, she went alone while her father accompanied Mrs. Lindner to chemotherapy appointments. During that summer, her mother's bedroom door, always open, stayed closed.

Now Deborah reminded her what she had always said about her chemotherapy. Her eyelashes, once long and curly, had been rendered short and stubby. Food tasted different. It had, in so many subtle ways, aged her.

"I don't want that for myself," Deborah said. "I don't want to treat cancer. I just never want to get it."

She began to seek support elsewhere. A genetic counselor gave her a brochure for Bright Pink, a group of young women who have tested positive for the BRCA genes. Lindsay Avner, its 24-year-old founder, lived in Chicago, and their meeting over coffee in the hospital lounge one evening in March lasted four hours. Ms. Avner had had a prophylactic mastectomy last year.

"You've got to see my breasts," she told Deborah, escorting her into the bathroom.

Ms. Avner's surgeon at [Memorial Sloan-Kettering Cancer Center](#) in Manhattan had used a technique that preserved the breast skin and nipples, leaving a scar only under the breast.

Deborah, still in her scrubs, said, "Wow."

Mr. Zehr drove her to an appointment with Geoffrey Fenner, the chief of [plastic surgery](#) at Evanston Memorial Hospital one evening in mid-April. If she could find a surgeon to perform the mastectomy, Dr. Fenner said he would perform the reconstruction.

The nipple-sparing technique, the doctor explained, is not popular in the United States; a decade-old study suggested that leaving the nipple increased the risk of cancer. But more recent research indicated that the risk was perhaps only 1 percent greater than with traditional reconstruction.

"I can live with that," Deborah said.

Mr. Zehr, a corporate insurance underwriter, waited outside. On the car ride home, Deborah lobbed her question into the darkness.

"Does the thought of plastic surgery bother you?" she asked.

A moment passed.

"It would if I thought the person I was with was doing it because they didn't like the way they looked," he said. "But that isn't this situation."

He looked at her. "So, no, it doesn't bother me."

Deborah announced her intention to have surgery in a long e-mail message to family members at the end of April.

“I want to share with you what I feel is the right answer for me,” she wrote.

Like anyone who carried the defective gene, she might never get cancer, she acknowledged. Or she might only get it when she was old. “But I’m not a gambler,” she wrote.

Her aunt, Gloria Spurlock, a music teacher in Louisville, Ky., immediately called Mrs. Lindner, her sister, at her home in Des Moines.

“How could you let her dismember her body?” she demanded. “You have to talk her out of it.”

Stung, Mrs. Lindner tried to defend her daughter. But Mrs. Spurlock was voicing some of her own worst fears.

“Gloria,” she replied. “This is Deb’s decision.”

It was the first of several heated phone calls between the sisters. Mrs. Spurlock had considered getting tested after Mrs. Lindner found out she had a BRCA mutation. The sisters knew the gene must have come from their mother, who had had ovarian cancer a decade earlier, and whose own mother had died of the same disease. But Mrs. Spurlock concentrated instead on a healthy diet, rest and positive thinking.

The medical profession, she had long believed, was far too eager to administer drugs and remove body parts that could be healed.

Mrs. Spurlock’s daughter, Lisa Spurlock, 24, also expressed dismay.

“I’m sorry you have to be so scared of this disease,” Ms. Spurlock wrote to her cousin.

The reactions gave Deborah pause. Then they made her angry.

“Why are they saying things like this to me?” she demanded of her mother.

From the Philippines, her sister suggested that Deborah was exposed to the worst-case scenarios as a doctor. Can’t breast cancer often be cured?

“You’re right, it can often be cured,” Deborah wrote back. “The problem is that the cure involves cancer, surgery, chemotherapy, sometimes radiation and the possibility of metastasis and death.”

When a second surgeon in Chicago gave the idea of the preventive mastectomy a lukewarm reception because of her age, Deborah flew to New York for a consultation with the doctor who had performed Ms. Avner’s surgery. She invited her mother to come with her.

On the plane, Deborah showed her mother a PowerPoint presentation she had created, making the case for preventive surgery. Mrs. Lindner listened. But mostly she watched the relief in her daughter’s face as she talked about escaping her genetic prognosis.

It was there again the next day in Dr. Patrick I. Borgen’s office on Park Avenue, when the doctor supplied the first unconditional medical affirmation of Deborah’s view.

“Maybe your grandchildren will have better options,” said Dr. Borgen, director of the Brooklyn Breast Cancer Project at the Maimonides Cancer Center. “But right now a draconian operation is the best thing we can do for you.”

Back home in Iowa, Mrs. Lindner asked her husband: "What would we have done? What if we had known when we were dating?"

"We would have done the same thing," he said. "We would have wanted you to live."

At Dr. Borgen's recommendation, Deborah scheduled the double mastectomy with Dr. D. J. Winchester at Evanston Northwestern hospital for the last weekend in June, three days after her medical board exam. Her insurance agreed to pay after requesting a letter of support from her surgeons. There would be just enough time to recover before she began practicing in the fall.

A Glance in the Mirror

But with the date fixed, Deborah, for the first time in months, began to doubt her decision.

Glancing in the mirror on her way out for a run, she looked herself over.

"I was like, all right, there's me, those are my breasts," she told a friend. "That is what I see."

It did not help that Mr. Zehr did not seem to quite understand what the surgery entailed. "I won't be able to breast-feed," she reminded him.

"I thought you were having reconstruction," he said, puzzled.

"Yes," she said, "but they'll be silicone."

With three days to go, Deborah met with a nurse to go over the details of the procedure she had discussed with the surgeon. She wanted to be sure about where the incisions would be, and the size of the implants.

"We had talked about the scars on the side," she told the nurse, "and not touching the nipple."

"Oh, you may have incisions everywhere," the nurse said. "There may be one up the front and underneath and up the nipple."

Deborah burst into tears.

"Am I doing the right thing?" she asked her mother from her cellphone after she left the office.

Mrs. Lindner, packing for the drive to Chicago to be with her daughter during her hospital stay, knew she was not just asking about the scars. And she had the answer.

"Yes," Mrs. Lindner said. "You are doing what is right for you."

On the morning of the surgery, Mr. Zehr was there, holding Deborah's hand. "You look cute in your gown," he told her.

In the lounge, Mrs. Lindner waited. The surgery and reconstruction took seven and a half hours, twice as long as the doctors had expected. The incisions were small, Dr. Winchester explained when he came out, and hidden under the breast, so it had taken a long time to scrape out all the breast tissue.

Then Mrs. Lindner rode up in the elevator with her daughter, still unconscious from the anesthesia. As they arrived at their floor, Deborah opened her eyes.

"Mom," she said, and managed a small smile.