

Sarah Roth //

The Genetics Department at Children's National Medical Center in Washington, D.C. displays hundreds of pamphlets in the waiting room, stacked at every corner table. Some of them I recognize, having revised them back in the office. The pamphlets have titles like: *What is My Family Tree Telling Me?* and *PKU and You*. They feature cartoon characters, speech bubbles, and what we thought, months back, were cheerful fonts. With one hand, I sift through them, and with the other, I gather my sweater closer to my body. My partner, Sam, sits on the couch, peering into his laptop. The static of pop music streams through overhead speakers. Hearing my name, I approach the receptionist to deliver my health insurance card. My hand is shaking, ever so slightly, and I quickly place the card at her window and return to the couch. Sam glances at me. A door opens. The genetic counselor emerges. She is a young woman with cropped blonde hair, perhaps ten years my senior. She wears a tweed suit.

"We're ready for you, Sarah," she says.

Sam and I follow her past a children's play area, where an array of toys is scattered. There are no children to be seen. We follow her into a bare, beige room, and we sit in the patient's corner. The genetic counselor sits at a desk. She is the picture of composure, exuding calm. She makes me want to be a picture of composure, too. A gynecological oncologist enters, and she sits, clasping her hands in her lap. She is prim and professional, the eldest in the room. In the past three months—on email threads, over the phone, and through a series of meetings—the genetic counselor and I have prepared for this appointment. We constructed a family tree based on my relatives' experiences with cancer; discussed my anticipated feelings in the case of any diagnosis; considered the recommended actions, available support systems. We discussed survivor's guilt. We discussed the conversations I might have with my sister, mother, and father. The counselor and oncologist turn towards me.

"How are you feeling today?" the counselor asks.

"I'm okay," I respond. Last week, I mention, back at home, my mother discovered that her ovarian cancer is returning. She phoned me this morning. It was detected through a routine CA-125 test. "Promise me," she said. "You'll find out." I opt not to share this vow with the counselor.

The counselor nods. "I'm sorry to hear that," she says. There is an expectant hush, as she, the oncologist, and Sam each appraise me. Leaning forward, I look at the wall, where a framed

diploma is hanging.

“I’m ready to know,” I say. “I think.”

“Great,” she says. She smiles gently, presses her fingertips together. The oncologist smiles, too, mirroring. Another moment of quiet passes, and then. “Well. We have received the results of your test.” The counselor purses her lips and opens a manila folder. “I’m sorry, Sarah. You *are* a carrier of a *BRCA1* harmful mutation.” She looks at me from beneath her eyelashes. All three look at me carefully. Sam places his hand on my knee.

“Oh,” I say. “I thought I might be.”

“Some further information,” the counselor says, handing me a thin booklet stamped with the Myriad logo.[1] *Understanding Your Positive Result: A Guide to Understanding Your Risk and Taking Action*. It has a red stripe with a plus sign on the cover. It is full of statistics, suggested courses of action, and referrals. It informs me that, by age seventy, I will have an 87% risk of developing breast cancer, and a 63% risk of developing ovarian cancer.[2] A chart demonstrates that risk increases with age. Risk also depends on a number of factors, I am told, but these factors are not highlighted in the booklet. The booklet notes that I will begin annual, clinical breast examinations at age twenty-five, as well as annual MRIs or mammograms; I might consider experimental screening studies and a risk-reducing mastectomy; and I might pursue risk-reducing chemical agents such as Tamoxifen. It notes that I will begin to measure my CA-125 levels at age thirty-five, and I will consider the bilateral removal of my ovaries when between the age of thirty-five and forty. These numbers and procedures are, by now, familiar to me. They have the appearance of facts. My body has already connoted these numbers; now it will denote them. When I open the booklet, a single sheet of printer paper slips out. The counselor has provided the contact information for seven breast surgeons, five plastic surgeons, and one gynecological surgeon in the metropolitan area.

“For when you’re ready,” she says. “Just call them and tell them you are *BRCA* positive.”

The counselor asks Sam if he has any questions, and if we have an idea of when we would like to have children. “It would be best before thirty,” she says. “Early thirties at the latest. If you plan to breastfeed.” Sam and I shrug, as respectfully as we can, as this is not yet a consideration. My breasts have just become objects of pleasure. They are not yet objects I would associate with nurturing. We have barely discussed the possibility of future children. The counselor tells me she will check in tomorrow. We leave the Genetics Department and walk slowly through the hospital, winding our way through the corridors. We look around as if we are searching for something, or on our way to visit a family member. It is early March, and through the windows, the sun slants onto prints inspired by genetic concepts.

Outside, the air is brisk. The sun is melting away the last of a recent snow. We find the car and drive to a nearby plaza, where we settle at a café. My body feels heavy, like I carry the weight of this new information in my chest and stomach. The world seems particularly quiet. My life stretches before me, as it did before. But now there are these stitches in the years, these actions I must take to

forestall an almost certain illness. As soon as I turn my mind away from the numbers—sending a few emails for work, looking at the tasks on my calendar—I am brought back by the sensations in my body. By the very sense of my heart beating in my chest cavity, by the subtle ache of an expected ovulation, by the twitches that occur, at my eyelids, at my neck, without my intent. In my notebook, I write what I know. My name is Sarah Roth, and I am twenty-four years old. I live in Washington, D.C. In my DNA, I carry a *BRCA1* harmful mutation. My risk is growing.

The genes now known as *BRCA1* and *BRCA2* were discovered in the 1990s, at the dawn of the Human Genome Project. Across laboratories in Seattle, Bethesda, Salt Lake City, Tokyo, Tel Aviv, and elsewhere, groups of scientists competed to locate, isolate, and clone two stretches of nucleotides along the seventeenth and thirteenth chromosomes.[3] Knowledge about these genes emerged from milieus at once collaborative and combative. Notes within laboratories, phone calls among colleagues, press releases, scans, and interviews traveled and translated across epistemic borders; conferences brought together individuals, families, researchers, and providers to enact genetic meanings.[4] “*BRCA*,” the name given by the Human Genome Organization’s committee on nomenclature, is an acronym for “breast cancer,” though “breast cancer gene” is a simplification. The *BRCA* genes are two among many tumor suppressor genes, which code for proteins that contribute to DNA repair and transcriptional regulation.[5] Their purview is tissue of the breast, ovaries, fallopian tubes, uterus, pancreas, and, in men, the prostate. With a nucleotide deleted, added, or misplaced in a *BRCA* region, a cell that divides incorrectly might form a cancerous cell, and then another, and then another, until, without regulation, the cells cluster in the shape of a tumor. My mutation, the Myriad booklet tells me, is “5266dupC.”[6] Geneticists say the mutation originated in northern Europe, in the body of one ancestor, some fifteen- to eighteen-hundred years ago.[7] Mine is the most common of the *BRCA* mutations, this duplication of one cytosine on the long arm of the seventeenth chromosome.[8]

It is night when my mother calls again. She puts me on speakerphone, so I speak to my parents together. It seems this information is more difficult, and perhaps more real, for them than for me.

“I’m so sorry,” my mother says. “This is a mother’s worst nightmare.”

“You’ll schedule an MRI,” my father asks, his voice caught in his throat. “Soon?” The question is not a question. They are also heavy with concern. They have begun to consider my mother’s next course of treatment with her oncologist. Her last course is a clear and recent memory. Relics of chemotherapy—Cold Caps, anti-nausea medications, canes, uneaten frozen dinners, breakfast trays—litter the corners of the house. The couches are arranged in such a way. She is still visiting the hospital to flush her port each month. He is still taking anti-depressants. Her hair grows in wisps. He asks, on occasion, how she would like her funeral arrangements. Risk places my parents on some borderlands from which they may peer, expectantly, into Susan Sontag’s proverbial kingdoms of the living and ill. Risk clouds some horizon of comfort. As risk catches up to reality, they begin to feel vulnerable. Now I am marked as vulnerable.

“Sure,” I say. And so my body joins the family effort.

It is not uncommon for those affected by hereditary cancer to seek out genetic testing.<sup>[9]</sup> In fine-grained works of creative nonfiction, *Pretty is What Changes* and *Blood Matters*, Jessica Queller and Masha Gessen explore their experiences of diagnosis as embedded in relationships with their mothers. For each woman, assuming the identity of ‘high risk for cancer’ requires reflecting on her mother’s symptoms; writing through the texture of her relationship; and interrogating the ways in which this relationship does or does not *make sense* in the context of the diagnosis. Through storytelling, each woman negotiates the connection between the body of the mother and the body of the self. Masha Gessen is a journalist by training, and Jessica Queller is a screenwriter. In their thirties, and mid-way through their careers at the time of writing, the two authors integrate their professional genres with pathography. Their writing engages an elegiac politics.<sup>[10]</sup> They invite recognition of pain and suffering often erased from the narratives of women who encounter hereditary breast and ovarian cancer.<sup>[11]</sup>

Masha Gessen begins *Blood Matters* with the story of her mother’s death. It is August 1992. Masha is at a retreat with colleagues in Palm Springs when, in the night, she feels an inexplicable wave of nausea. She walks to the bathroom, splashes water on her face. At dawn, she calls her parents in Boston. A policeman hands the phone to her father. Masha learns that her mother, whose cancer has spread to the bones and liver, has died. She comes to understand that, in the night, she felt her mother’s pain through and in her body. “My inextricable physical relationship with my mother,” Masha writes, was “proven to me for the first time—at the moment hers ended.”<sup>[12]</sup> Fourteen years later, their physical relationship proves itself again. She is at a coffeehouse in Cambridge. She receives a call from a genetic counselor, and is informed that she carries a deleterious mutation on the *BRCA1* gene. Though she has requested the test, Masha is shocked. She has assumed she inherited nothing from her mother. They have had an estranged relationship; they are not alike. But this understanding is overturned by new genetic information. “Then I found out I got everything from her,” Masha writes. “Including the flaw that killed her.”<sup>[13]</sup>

Jessica Queller also begins *Pretty is What Changes* with the story of her mother’s death. It is December 2001. Jessica’s family gathers in the NYU emergency room. Her mother’s abdomen is swollen like a melon, and she is vomiting. This is often how ovarian cancer presents itself: late. Laproscopic surgery reveals it to be stage IIIC. She is given a prognosis of five years. Jessica frames her memoir with this prognosis, mirroring the dramatic contortion of time that she, and her family, experiences through the prediction of her mother’s death. The reader knows how this story will end. “*Five years to live?*” Jessica writes. “It was worse than anything we could have imagined. In fact, she would live less than two.”<sup>[14]</sup> Weeks later, as her mother begins treatment, Jessica is introduced to the head of a foundation dedicated to women’s cancer prevention. The woman asks Jessica to tell her the story of her familial cancer. “Because of your mother’s history,” the woman says, “you’re now in the highest-risk category. You’re the perfect candidate for the genetic test.”<sup>[15]</sup> As Jessica is introduced to the possibility of assessing risk, her story is scaffolded by her mother’s dwindling prognostic time.

My mother begins a new regimen of chemotherapy, and I decide to spend some time in Florida. She receives Carboplatin on Tuesdays at Moffitt. On days when I am not at the university, I visit. Even then, not as often as I should. My father holds court with a sack of Cliff bars and graham crackers in his lap. My parents' friends stop by to keep company. In the late afternoon, when it is time to leave the hospital, we convene at their home. We sit in the backyard, listening to the sounds of the fading afternoon. Or we sit in the living room, under piles of blankets, waiting for the effects of steroids to ebb and flow. Or, listless, we walk until evening. The regimen is effective. The CA-125 numbers return to a normal range. The treatment ends. For months, my mother exists as if cancer was always a dream. Sometimes, her doctors urge her to search for prophylaxis. Other times, they say, "enjoy yourself." She does. Risk becomes a game, a trick, a friend and an enemy. It lives in the blood. It lives on monitors. It lives on sheets of paper. I am ever coming and going. I go.

The field of genetic counseling is predicated on the dispensation of genetic information in the form of dispassionate facts. In 1969, the first graduate program in genetic counseling was established in the United States, at Sarah Lawrence College.[16] With the development of noninvasive fetal testing technologies—amniocentesis and chorionic villi sampling—and the decriminalization of abortion, genetic counselors began to play an increasingly significant role in counseling women on and around fetal genetic risk.[17] Influenced by the work of psychologist Carl Rogers, early genetic counselors applied 'nondirective' methods of engagement; clients, not counselors, would set the eventual goals for therapy.[18] The rhetoric was not dissimilar from a feminist body politics centered on rights, ie. a woman has the right to do what she wants with her body. The new wave of genetic counselors, mostly women, replaced PhDs in genetics, mostly men, as providers of guidance. Counselors could withdraw from asserting value judgments, particularly about whether a woman should, or should not, terminate a pregnancy.[19] The woman thus maintained the right to choose.

In the 1980s, the first predictive genetic tests for adults emerged. The tests, which involved blood samples from multiple family members, could roughly predict the risk of developing symptoms for Huntington's Disease. When, in the mid-1990s, predictive tests became available for an array of familial cancers, including *BRCA*, the field took off. Counseling on and around such conditions became a priority for members of the American Society of Human Genetics, especially as the testing industries gained traction. At the same time, team management of breast cancer became popular in United States breast cancer clinics. Select hospitals opened 'risk clinics,' gathering gynecologists, oncologists, genetic counselors, nurse practitioners, and social workers within one institution.[20] Unlike genetic counselors focused on fetal testing, counselors placed at 'risk clinics' would belong to a thought collective with a goal. Not to extend the life of an individual, nor to improve her quality of life. The goal of a genetic counselor at a breast cancer clinic would, simply, be to prevent death from cancer.[21] In the 21<sup>st</sup> century, this involves a specific regime of practices. A tension has emerged in the field between nondirective guidance and the drive to detect, circumvent, and excise cancer in the era of risk.

The concept of 'genetic vulnerability' has emerged in the literature on genetic counseling to account for a form of distress connected to witnessing another person's experience with a



predicted illness. In a 2010 article in *Psycho-Oncology*, genetic vulnerability is defined as a ‘personal variable.’ For those at high risk for cancer, vulnerability is a barrier to pursuing regular surveillance and, if recommended, prophylactic surgery.[22] Vulnerability is represented by a single letter, a *beta* sign. It is placed on a chart alongside ‘self-esteem,’ ‘stigma,’ and ‘mastery.’ It can be explored by interrogating, together, an individual’s perceived family history and statistical genetic risk.[23] Though it pertains to interpersonal experience, the barrier exists at the site of the self—separating the individual and other at risk—and it can be addressed as such. The discourse of the professional, as Veena Das writes, often lacks the conceptual structures needed to speak on behalf of, or lend voice to, her interlocutor.[24] For those who learn that they are at risk for hereditary cancers, “scientific rationality” is often used to frame the present in terms of future danger; knowledge is targeted such that it might lead to the clinical management of this danger.[25]

Discourses of vulnerability in the literature on genetic testing gesture beyond the therapeutic discipline. All bodies, and not merely *BRCA* positive bodies, live in, with, and at risk, due to environmental, industrial, and institutional factors of our existence.[26] The modern subject lives within a matrix of risk, and the state has a lexicon to document it. In a given year in the United States, 11.7 percent of adults will be diagnosed with heart disease, and 633,842 will die with heart disease listed as the cause.[27] Over fifty thousand individuals will die with the flu or pneumonia.[28] The numbers are posted in our subway cars and in textbooks. David Armstrong has written that ‘new public health’ and its risk-factor epidemiology has created subjects charged with the responsibility of knowing risk factors for any given disease. With knowledge of risk, populations might avoid risky behaviors and continuously surveil themselves and others.[29] In the language of epidemiology, the mark of vulnerability is deployed to count some of our bodies as more surveillable than others.

Jessica Queller devotes the first half of *Pretty is What Changes* to the careful narration of her mother’s two years of living in prognosis. Jessica moves from Los Angeles to New York, finding a job at a show in the city. Her sister moves to New York, too. With their father, they become involved in the intricacies of their mother’s care. Her mother receives an IV treatment of Carboplatin and Doxil for a year. When the toxicity overwhelms her body, the family helps her decide to switch to Gemzar. Her hair thins, so Jessica and her sister take her to cut a wig with their favorite stylist. She is at times “flushed with the happiness of being alive,” at times just “sick.”<sup>[30]</sup> Through the prognostic years, Jessica notices a shift in their relationship. The shift occurs, somehow, through the care they share outside of the hospital. Jessica’s mother, she writes, described in passages as once cold and uncaring, “gradually and without my noticing, had grown maternal.”<sup>[31]</sup> As her mother begins to orient herself towards death, she comes to acknowledge her daughter in ways that she never had. “She told me she knew she didn’t have much longer to live,” Jessica writes. “I began to cry, and then she cried, too. But for the first time in our late-night talks, she focused solely on providing me, her child, with comfort.”<sup>[32]</sup>

Soon, Jessica’s mother stops responding to the chemotherapy altogether. Her CA-125 numbers rise. Her doctors suggest she forego treatment to enjoy her remaining days. She is given another prognosis: three months. She transitions to home care. She begins to communicate with her

daughters in an unmediated manner, losing the “filter that exists between impression and response.”<sup>[33]</sup> Jessica and her sister develop new modes of caring for their mother. They learn to press fentanyl patches onto her arm when she is in pain. They facilitate the delivery of her Compazine suppositories when her nausea becomes unbearable. They walk arm in arm with her when her gait falters. They pull her from bed when she is not able to lift herself.

“You have no idea what it’s like,” their mother says. “What it means, to have everyone caring for me like this. I can’t describe it.”<sup>[34]</sup> It takes metastasized cancer, reflects Jessica, for her mother to grasp what it means to nurture and be nurtured. “Care,” writes the philosopher Sandra Laugier, “is a fundamental aspect of human life, a set of various practices, dispositions, and feelings.”<sup>[35]</sup> The subject of care is sensible, passive, and caught in a web of relations; in a form of life that is social and biological; in hierarchies. Care is a practical response to specific needs. Care is sensitivity to the ordinary details that matter. Care, Laugier writes, reminds us that we need one another. The human life form is essentially precarious, vulnerable.<sup>[36]</sup> Given our fragility, there is a possibility for an ethics of care in responses to fissures and wrinkles, to fractures and tears, to even the smallest and most ordinary of textures that shift.

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Even as her body deteriorates, Jessica’s mother experiences flickers of life. Until the end, she comes alive, for instance, through wry dialogue with her daughters. In fact, she refuses to die—to give up speech—in their presence. The nurse describes her behavior as ‘end-state anxiety.’ Jessica’s mother describes her behavior as ‘fightability.’ “If it’s fightable, I’m fightable,” she says.<sup>[37]</sup> But her lungs fill with fluid, and she can no longer speak. She is given morphine, and, sedated, she passes away.

Jessica and her sister take over their mother’s shop. They sort through her belongings, put her house on the market, and grieve. One year passes. Reminded by a friend in the cancer prevention community, Jessica decides to draw blood for a genetic test. She tests positive for a *BRCA1* harmful mutation, and it is recommended that she visit a cancer care center to discuss the results. The prediction makes her feel as if she is living in a chilly, predestined future, but she is not surprised. She obediently follows up, scheduling an appointment to become a “card-carrying member.” Filling out forms in the waiting room, she witnesses women in various stages of cancer care passing her by. “It hadn’t occurred to me,” Jessica writes, “that the clinic would be part of a real cancer center with real cancer patients.”<sup>[38]</sup> She meets with a genetic counselor and begins surveillance, with an MRI, CA-125 test, and physical exams.

Jessica’s first encounter with the high-risk clinic unnerves her. The genetic counselor, a woman named Cheryl, recognizes her diagnosis as a tragedy. She speaks to her in a voice thick with sympathy. Her eyes are twin pools of pity. “Most women tell me their lives are split in half,” Cheryl says. “Life before they found out they carried the BRCA genetic mutation and life after. They say nothing was ever the same again.”<sup>[39]</sup> When Jessica realizes that Cheryl is expressing her sympathy because of the genetic diagnosis, and not in response to the loss of her mother, she is incensed. How could the counselor’s response be so misplaced? As Cheryl describes protective legislation

and lists the recommended forms of surveillance that she will begin, within moments, Jessica grows angry. She stares at the counselor, quiet and seething.

“How do you feel?” Cheryl asks, noting her demeanor.

“I *feel*,” Jessica says, “like you’re treating me as if cancer is imminent.”

Oblivious, Cheryl restates the statistics, gesturing to a stack of pamphlets. “You may want to consider chemoprevention or prophylactic surgery,” she adds, “like mastectomy or oophorectomy.”<sup>[40]</sup> Jessica leaves the appointment, and, shaking, heads to the ‘inner sanctum of the clinic’ for surveillance. “I was not sad or afraid,” Jessica writes. “I was indignant. How dare she smile and spew out those horrible statistics? And scare me with chemoprevention and prophylactic surgery? Mastectomy? Was she out of her mind?” In the clinical setting, Jessica experiences a disjuncture between the language of statistics and the language that she would use to describe her experience of genetic diagnosis. “And how dare she make me feel like I was in some kind of danger,” Jessica writes. “That was supposed to be therapeutic?”<sup>[41]</sup> Meanwhile, she mourns the loss of her mother. There is something grotesque about a barrage of numbers amid a recent memory of death.

In *Blood Matters*, Masha Gessen explores an initiation into the cancer clinic through surveillance. “Svenya and I walked silently to the parking garage,” she writes, “where I flashed my distinctive small blue Dana Farber card. I was a cancer-center patient now, and this qualified me for free parking.”<sup>[42]</sup> Masha, unlike Jessica, connects to BRCA providers over fourteen years after her mother’s death. Being subject to surveillance, she writes, is like working the front as a war correspondent. “I had lived this,” she writes. “You lie still as you can, usually surrounded by people you cannot see or feel, and you wait, listening. You name every noise. It is not frightening exactly: There is no adrenaline rush like you get when you run from a threat or stare it down. There is an eerie calm, and it is all in the waiting.”<sup>[43]</sup> And so she proceeds. She undergoes mammograms, MRIs, exams, ultrasounds and CA-125 tests. Unlike war, Masha realizes, the dangers of biomedical risk are not clear. As a professional patient, she will always be “ill until proven healthy.” She will need to prove her health again, months later, and again, after that.<sup>[44]</sup>

Masha and Jessica each balk at the way in which their providers recognize their bodies as already marked by danger. Masha feels the approach is not rational; Jessica feels the danger is not grievable. Masha asks her primary care physician to stop treating her like a cancer patient; she does not yet have cancer. Her physician responds: “You have no *detectable* cancer.”<sup>[45]</sup>

As a pathological phenomenon, identified by physicians and individuals, “cancer” has been described and recorded since antiquity.<sup>[46]</sup> But the diagnosis of cancer without symptoms only became possible in the twentieth century. As the historian Ilana Löwy has explored in *Preventative Strikes*, a history of preventative surgery in the United States and Europe, a continuum from the body at risk to the tumor-suppressor gene has been enabled by the development of scientific techniques and instruments for the early detection of cancer; changes in the treatment of cancer as a disease; and the adoption of ‘cancer schemata.’<sup>[47]</sup> The continuum that connects one’s



understanding of the body to one's awareness of the cell, Löwy argues, is made possible through "gradual public education" that trains us to view "images produced by scientific instruments and techniques" as extensions of our senses.<sup>[48]</sup> From American Cancer Society campaigns to biology textbooks, individuals are prepared to receive an MRI scan or CA-125 reading and, looking at it, see a reflection of their own bodies in danger.

Masha Gessen and Jessica Queller each approach an array of rational consultants before making a decision about how to manage their respective risk. Medical professionals suggest to each woman that she pursue preventative mastectomy, and that she consider an oophorectomy down the line. To grapple with this guidance, Jessica turns to her friends and family for advice, while Masha turns to colleagues and professors. Masha visits a professor of economics, determined to make a decision at any cost. He assesses the value of a life lived with or without cancer by drafting an Excel spreadsheet to quantify the relationship between risk, vulnerability, and the value of a life. In the left column, they enter Masha's age. Across the top, they write her options: Oophorectomy, Mastectomy, Oophorectomy and Mastectomy, Do Nothing.<sup>[49]</sup> Following an equation, the economist reaches the conclusion that Masha will have a more valuable life if she removes all potentially cancerous organs. By the end of the story, she has begun.

Through the act of writing *Blood Matters* and *Pretty Is What Changes*, Masha and Jessica each work through the 'choice' presented to them at the time of diagnosis. "An impossible choice," Masha writes. "Live and wait for the cancer to come, or start carving up a body that felt utterly healthy."<sup>[50]</sup> After witnessing their mother's deaths, becoming subjects of surveillance, and engaging rational tools to discern the meaning of risk, Masha and Jessica each choose to proceed with preventative mastectomy and reconstruction. Their bodies, marked as vulnerable, transform into postsurgical bodies. Their breasts, once sites of risk, become like shields.<sup>[51]</sup> They are still at risk for cancers. But their narrative quests, in the wake of reconstruction, find a kind of closure.

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My first experience with surveillance is at the Johns Hopkins Breast Center in Baltimore. It is the end of summer, and I have recently moved to the city. In this part of the story, I am alone. At home, I confirm my appointment through the MyCharts portal on my laptop. In the hospital, I enter my health insurance information on a touch screen. The technician is a middle-aged woman. In the waiting area, she places a pink band on my wrist. She leads me to a set of curtained stalls. Before I enter, she stops to look me up and down. "How old are you?" she asks. When I tell her I am twenty-five, she narrows her eyes. She believes there has been a mistake.

"We only see women over forty," she says. "I don't understand why you would be here."

"I have a referral," I say. "I have a genetic predisposition for cancer."

She shakes her head. "I'll ask the doctor," she says. "But I think somebody has messed up."

The inside of the stall is like the dressing room of a luxurious department store. It is warm and furnished. The lobed hooks on the walls have an ornamental quality to them. A dresser is stocked with folded cloth gowns in different sizes. Lifestyle magazines are spread in an array across the top. Pulling open a dresser drawer, I peel away my clothing and wrap a gown around my body. Though I cannot see them, I hear other women entering the stalls, getting settled, and waiting. I feel a sense of intimacy with these women, though I do not know anything about them.

The technician returns and, encouraged by a physician I have not seen, guides me to a room with a set of machines inside. She tells me that this will not be painful, just uncomfortable. Not to worry. She is still chuckling, incredulous at my age. As I behold the hulking mammography machine, I realize I haven't imagined what a mammogram would *feel* like. It feels like nothing I have experienced before. One by one, the technician pulls each of my breasts away from my body, placing them between two panes of glass. The glass compresses each breast, squeezing until I think it might burst. The machine records images as the glass panes close on each breast, first on the sides, then on the top and bottom. When the technician has finished, she asks me if I would like to see the images.

"Yes," I say. The images look like breasts to me, blank and inscrutable and white. "You have very dense breasts," she says. One week later, I receive an email and an alert on the digital patient portal. *No evidence of disease*, it says.

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[1] The logo reads: "Myriad: When Decisions Matter."

[2] Myriad Genetic Laboratories, Inc. "Understanding Your Positive Result: A guide to understanding your risk and taking action."

[3] Kevin Davies and Michael White, *Breakthrough: The Race to Find the Breast Cancer Cure*. New York: Wiley, 1995.

[4] Jane Gitschier, "Evidence is Evidence: An Interview with Mary-Claire King," *PLOS Genetics*, 2013.

[5] K Yoshida, Y Miki, "Role of BRCA1 and BRCA2 as regulators of DNA repair, transcription, and cell cycle in response to DNA damage," *Cancer Science* (95)11, 2004.

[6] Myriad Genetic Laboratories, Inc. "Understanding Your Positive Result: A guide to understanding your risk and taking action."

[7] Nancy Hamel, Bing-Jian Feng, et al. "On the origin and diffusion of BRCA1 c.5266dupC (5382insC) in European populations." *European Journal of Human Genetics*, 2011.

- [8] Hamel, "On the origin and diffusion of BRCA1."
- [9] See exploration of the literature in Masha Gessen, *Blood Matters: From Inherited Illness to Designer Babies, How the World and I Found Ourselves in the Future of the Gene*, 2008.
- [10] Lochlann Jain, *Malignant: How Cancer Becomes Us*. Berkeley: University of California Press, 2008.
- [11] Ilana Löwy, *Preventative Strikes: Women, Precancer, and Prophylactic Surgery*, 221.
- [12] Masha Gessen, *Blood Matters*, 4.
- [13] Gessen, *Blood Matters*, 6.
- [14] Jessica Queller, *Pretty is What Changes: Impossible Choices, the Breast Cancer Gene, and How I Defied My Destiny*. New York: Spiegel and Grau, 2009.
- [15] Queller, *Pretty is What Changes*, 21.
- [16] Alexandra Stern, "A Quiet Revolution: The Birth of the Genetic Counselor at Sarah Lawrence College, 1969," *Journal of Genetic Counseling*, 2009.
- [17] Errol Norwitz and Brynn Levy, "Noninvasive Prenatal Testing," *Review of Obstetric Gynecology*, 2013.
- [18] Gessen, *Blood Matters*, 81.
- [19] Gessen, *Blood Matters*, 79.
- [20] Ilana Löwy, *Preventative Strikes: Women, Precancer, and Prophylactic Surgery*, 180.
- [21] Gessen, *Blood Matters*, 80.
- [22] "Genetic Vulnerability," *Psycho-Oncology*, 2010.
- [23] Rebekah Hamilton and Barbara Bowers, "The Theory of Genetic Vulnerability: A Roy Model Exemplar," *Nursing Science Quarterly*, 2007.
- [24] Veena Das, "The Anthropology of Pain," *Critical Events: An Anthropological Perspective on Contemporary India*. Oxford: Oxford University Press, 1999.
- [25] Löwy, *Preventative Strikes*, 212.
- [26] See Joseph Masco, *The Age of Fallout*.

[27] National Health Interview Survey, 2015.

<[https://ftp.cdc.gov/pub/Health\\_Statistics/NCHS/NHIS/SHS/2015\\_SHS\\_Table\\_A-1.pdf](https://ftp.cdc.gov/pub/Health_Statistics/NCHS/NHIS/SHS/2015_SHS_Table_A-1.pdf)>.

[28] CDC. Health, United States, 2016. <<https://www.cdc.gov/nchs/data/abus/abus16.pdf#019>>.

[29] Marin Klawiter, *The Biopolitics of Breast Cancer*.

[30] Queller, *Pretty is What Changes*, 54.

[31] Queller, *Pretty is What Changes*, 54.

[32] Queller, *Pretty is What Changes*, 63.

[33] Queller, *Pretty is What Changes*, 66.

[34] Queller, *Pretty is What Changes*, 72.

[35] Sandra Laugier, "Politics of Vulnerability and Responsibility for Ordinary Others," *Critical Horizons*, 2016, 207.

[36] Laugier, "Politics of Vulnerability and Responsibility for Ordinary Others," 208.

[37] Queller, *Pretty is What Changes*, 77.

[38] Queller, *Pretty is What Changes*, 88.

[39] Queller, *Pretty is What Changes*, 89.

[40] Queller, *Pretty is What Changes*, 90.

[41] Queller, *Pretty is What Changes*, 90.

[42] Löwy, *Preventative Strikes*, 83.

[43] Gessen, *Blood Matters*, 73.

[44] Gessen, *Blood Matters*, 74.

[45] Gessen, *Blood Matters*, 74.

[46] Löwy, *Preventative Strikes*.

[47] Löwy, *Preventative Strikes*, 7.

[48] Löwy, *Preventative Strikes*, 7.

[49] Gessen, *Blood Matters*, 89.

[50] Gessen, *Blood Matters*, 84.

[51] Gessen, *Blood Matters*, 84.