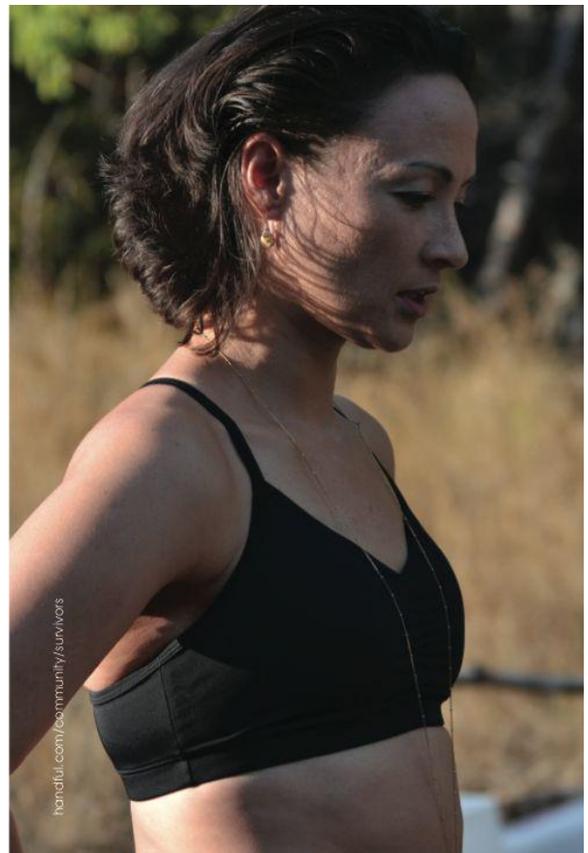


CARY GOLDBERG

[my cancer story, as excerpted from a speech given at Genentech in June 2012]





My story begins with a lump because I've never had a mammogram and am still not yet old enough to qualify for one. Throughout my 20s, I regularly performed self-exams because it was recommended in those days, and I was a health-conscious person who didn't want to get breast cancer. I knew that having a baby before age 30 decreased your chances as did breastfeeding, so I had my check sheet ready and was going to be certain to do whatever I could to avoid it. And not because I had any family history to speak of. In fact, I was supremely cocky back in the day,



telling my New York City Ashkanazi Jewish husband with a family history riddled with all manner of cancers, that being the first of his family to marry a non-Jew was an anti-cancer insurance policy! Yes, I was that obnoxiously confident in my genes. I was bringing the hardy, tofu-eating, cancer-free Asian genes to bear on our offspring. I wonder now if my fixation on avoiding cancer was my body subconsciously preparing me for the fight of my life. But I digress.

Receiving a diagnosis of breast cancer before age 40 usually means you are fortunate enough to have a palpable tumor close to the surface instead of deep against your chest wall, but by the time you can feel it, it's usually been growing there 8-10 years and thus, often turns out to be more advanced. Looking back,



I now know that three years before I could feel the lump, the same area flared with a painful swelling just a few days after the birth of my first child, Natalie Rose. I consulted the internet and my “What to Expect” book series on pregnancy, dutifully called my doctor and was given a prescription for antibiotics over the phone because it was chocked up to mastitis, a garden variety infection of the milk ducts, and off I went into the bliss and exhaustion of new motherhood, without a second thought.

Three years later, I'm blessed with a second daughter, Lindsey Hope, and my life is unfolding exactly as planned. In the summer of 2006, I'm standing in the shower, and I've got Cary's trusty to-do checklist ready. Today is monthly self-exam day. And there it is.... What's *that*? It's my imagination, right? That wasn't there last month? Why do I think it's something? It's nothing right? It *has to be* nothing.



I can remember reassuring myself, “it’s only been 9 months since your last exam. The responsible thing to do is wait until the yearly check up.” Every night I would lie in bed and probe it, bouncing between it’s *something*...it’s nothing. Asking my husband is it something, is it *nothing*? Telling a girlfriend about it and seeing her face shift—the first time I saw my fear reflected in another—that

was when I realized I couldn't sit on my hands anymore. But three months, what was three more months? When you have an extremely aggressive subtype of breast cancer like Her2+ with a grade 3 proliferation rate on a scale of 1-3, three months makes a big difference.

The lump grew from a pea to a marble, with no pain, just a haunting, hollowed out feeling when I would breastfeed. Because we had just moved to Lake Oswego, I asked my new preschool mom friends for OB/GYN recommendations. When I called the clinic for an appointment, I was told new patients were booking three months out. I made a fateful decision to mention the lump. Good thing I did because an appointment magically appeared for me the next day.

I bonded with my new OB/GYN over childbirth philosophy chit chat and my desire for a third baby. Those were my last moments of naïve planning for how life was *supposed* to be. The famous words of John Lennon rang true for me,



“life is what happens to you when you're busy making other plans.” We moved on to the exam, and I pointed out the lump. The doctor very matter-of-factly palpated it and pronounced, “Smooth...round...moveable—*all benign characteristics....*” I still play the “what if” game and ask, “what if he had stopped there?”

But he didn't. He continued, "but just to be safe, it's probably nothing, no need to phone your husband, let's send you for an ultrasound."

I'm lying on the gurney and the ultrasound wand keeps probing. More gel is being squirted, and the tech continues circling, pressing again, and again, and again. The tech makes audible clucking sounds and gentle sighs. She finally decides to call in a radiologist on the spot. Another tech and a second white coat gather around the glowing screen, the four of them blocking my view in their suddenly quiet huddle. I know it can't be good. I know what this is going to turn out to be.

To make sure the visceral matches the visual, the radiologist takes over and introduces the concept of a core needle biopsy. I get it—a hollow point needle that will draw out some samples for pathology to make sure it's malignant and not just some harmless benign growth. I am entirely unprepared for the gunshot that explodes over and over inside my tumor as tubular chunks are cut out and drawn up into the core needle syringe that looks like a space age, gleaming silver gun. It was the most physically painful part of treatment, perhaps because piercing the place that held all manner of toxic cells triggered an emotional catharsis as I began a free fall into the unknown. Fortunately my husband had been called in for *this* procedure. He held my hand, and the fear written on his face will be seared in my memory forever. I ask to see the tiny little squiggles of pink flesh that are suspended in a cup of clear liquid—how can *that* possibly be cancer?

The pathology comes back Invasive Ductal Carcinoma, estrogen positive, fast-dividing, and Her2+, which was presented as another marker for a particularly aggressive kind of breast cancer. Five years ago when I did internet research, there was still a lot of old thinking on the message boards and medical sites about what it meant to be Her2+. It wasn't a good thing, it meant your cancer was bad, more deadly, more tragic when it struck. It represented 20% of all breast cancer. The 20% that you used to cross your fingers and hope you weren't a part of.

They kept saying it's probably stage 1, with no positive nodes, and lumpectomy will get it all, you don't even need to consult a plastic surgeon, but *nothing* about my diagnosis went according to plan. The first PET scan revealed nine glowing lymph nodes under my arm. The tumor wasn't huge, but *damn*, it was aggressive, spreading its tentacles through my armpit. I couldn't help but wonder where else in my body those cells were traveling to.

At the very first appointment with my oncologist, I was presented with a personalized chart that visually represented what the statistics said about my chances of surviving.

Shared Decision Making

Name: _____ (Breast Cancer)

Age: 33 General Health: Excellent

Estrogen Receptor Status: Positive Histologic Grade: 3

Tumor Size: 2.1 - 3.0 cm Nodes Involved: 4 - 9

Chemotherapy Regimen: Third Generation Regimen

Decision: No Additional Therapy



6 out of 100 women are alive and without cancer in 10 years.

94 out of 100 women relapse.

Less than 1 out of 100 women die of other causes.

Decision: Hormonal Therapy



14 out of 100 women are alive and without cancer because of therapy.

Decision: Chemotherapy



27 out of 100 women are alive and without cancer because of therapy.

Decision: Combined Therapy



45 out of 100 women are alive and without cancer because of therapy.

If I did nothing, 94% chance of dying in ten years. Not liking that long red line AT ALL. Undergo hormone therapy and chemotherapy, and you'll get yourself up to about a 45% chance of living ten more years. Ok, still not a huge fan of that red line. I can tell myself until the cows come home that I'll make it my business to be in that green/yellow zone, but given my excellent health

and highly conscious lifestyle choices to do whatever possible to avoid breast cancer, I shouldn't have been anywhere near that red line in the first place.

At the bottom of the chart, the doctor had to hand-write what would happen if I added biologic therapy, namely Herceptin, to my treatment plan. Wherever I was on that number line would be cut in half. I asked the doctor to repeat himself, "whatever number you're at after combining hormonal and chemotherapy treatment, you add Herceptin and you increase your chance of surviving by 50%." Now those were numbers that I could embrace, and I said yes to the full meal deal. I'll do it all, I'll leave nothing on the table, throw everything but the kitchen sink at me, but give me that Herceptin that ups my survival rate 50%. It's quite an additional rider to the insurance policy. I understood it to be a numbers game, but I sure liked those numbers, and I held on to them, feeling incredibly blessed to have such a powerful tool in my arsenal to aim at these rogue cells running amok.

We decided that starting with systemic treatment made more sense in my case than having surgery and waiting to recover before starting chemotherapy. I was prescribed four months of dose dense chemotherapy.



The trusty old poisons were trotted out and administered—the so called “red devil” of chemotherapies, Adriamycin, that was so thick it couldn't even be suspended in an IV bag but had to be hand pushed by the chemo nurse via 2 large plastic syringes directly into a central line that had

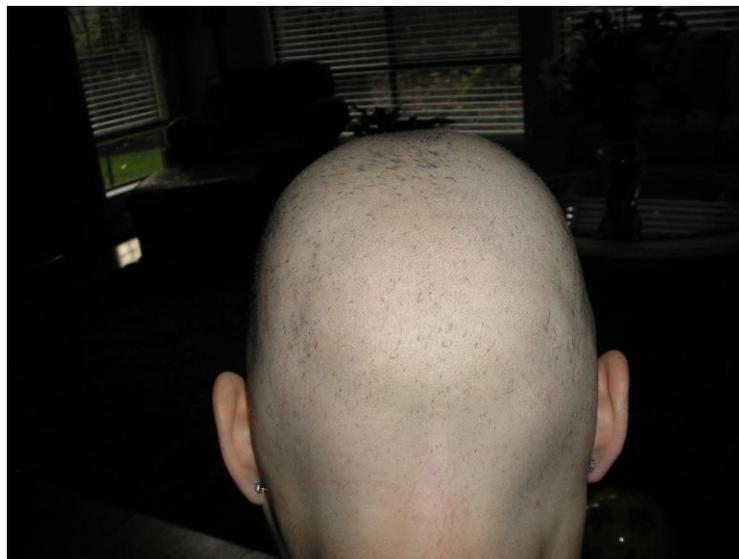
been surgically implanted in my vena cava. Then Cytoxan, whose very name was synonymous with cell death and the physical side effects that go along with such a blunt and inelegant instrument. Yeah it kills the cancer cells, but it takes down a lot of fast growing, perfectly normal cells too. I was subjected to the two drug combo for two months. Then I moved on to two months of Taxol, which I thought would be easier since it is derived from a tree that grows right here in the Pacific NW, but in my weakened state, that drug proved to be hell on wheels as well, leaving me in chronic pain, with white cells decimated, and very poor quality of life.



And all the while, my family is being held together by my little Korean mama who quietly moved in and cooked her worries away. My baby is tied onto her grandma's back in the Korean fashion,



and my four year old holds the apron strings, and all I can see are their big eyes, intently watching over my mom's shoulder and up at the stove as she methodically stirs the pots and pans, making my favorite dishes, brewing special teas and boiling bone and seaweed and mushroom soups that are medicinal foods in Korean culture. My daughters say they want to be a scientist and a chef when they grow up, and I couldn't be more proud when they say it because I believe both research and food hold the answers to cancer's cure and prevention.



So bald and weak after finishing chemo and wondering what happened to my life and how to ever pick up the pieces, it's time for surgery. Lumpectomy, right? We try and don't get clean margins. The surgeon is certain that he can get it with another go. Ok, I'll have a mismatched set, but at least I get to keep the girls. The second time he takes a 10 cm piece, but it comes back with more unexpected tumors that didn't show up on any scans. He's sure a third time will be a charm, but at

this point, I'm done, I'm terrified, and I can't trust that the surgeon can ever cut it all out. So I tell him to take both breasts, and my surgeon and my oncologist are visibly relieved by my decision and each privately say, "it's what I would have wanted my wife to choose."



The three surgeries to remove cancerous breast tissue and all the lymph nodes under my arm have delayed radiation to the point where the radiation oncologist insists we can't wait anymore and must begin the following week. The pathology report says I did not get a complete pathological response to chemotherapy. There were still living and dividing cancer cells in the breast tissue and in the nodes under my arm after chemo. So if they were still alive inside the tumor itself, what about those cells in my blood stream, the ones that are floating around looking for a new organ to grow in?

Reconstruction was dropped as an option because in my case staying alive was ultimately far more important than delaying treatment for replacement boobs. In my radiation mapping appointment where the black dots that delineate the radiation field are permanently tattooed on the skin, that's when I first hear that I'm actually late stage three. I proceed with the maximum dose of radiation with a boost thrown on top for good measure. Radiation is another effective yet crude treatment modality. It kills those cancer cells left behind regionally, but I'm still paying the price five years later for that 7 week course of invisible energy beamed at me. My chest wall is frozen and I'm in constant pain, and oh yeah, radiation can also *cause* cancer, so it's the gift that will keep on giving for the rest of my life.





After radiation, I'm burnt and bald, but I'm still alive, so I keep putting one foot in front of the other and wonder how much longer my mom can keep my family going, how much more dire news my husband can take. Those little hands that cling to me feel cloying when I just want to crawl in bed and shut the world away.



During radiation, my ovaries start to wake up from their chemo-induced menopause and produce estrogen.



I'm starting to feel like my old self again, like a red-blooded American woman. But wait, that's not a good thing because the estrogen faucet in my body needs to be shut off. So a month after finishing radiation, I have to have my ovaries and uterus removed in order to be eligible for a type of hormone therapy usually reserved for older, post-menopausal women. The only way for me to be like them is chemical or surgical menopause.

It is in this state of tentative healing and recovery, from a place where I've lost every organ that made me *biologically* female to cancer's assault on my body, that I finally embark on the part of my story where you all come in. It's time for the extra insurance policy! But after learning that chemo didn't work for me, I know that this elegantly targeted biologic therapy that will seek out and destroy Her2 cells is not really an added insurance policy. It's actually the drug I've needed all along to turn this sinking ship around. It's Herceptin that's going to save me.

Shared Decision Making

Name: Cary Goldberg (Breast Cancer)
Age: 33 General Health: Excellent

Estrogen Receptor Status: Positive Histologic Grade: 3
Tumor Size: 2.1 - 3.0 cm Nodes Involved: 4 - 9
Chemotherapy Regimen: Third Generation Regimen

Decision: No Additional Therapy



- 6 out of 100 women are alive and without cancer in 10 years.
- 94 out of 100 women relapse.
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Decision: Chemotherapy



- 27 out of 100 women are alive and without cancer because of therapy.

Decision: Combined Therapy



- 45 out of 100 women are alive and without cancer because of therapy.

Decision: Add Herceptin



- 72.5 out of 100 women are alive and without cancer because of therapy

I think it's important to note here that women today are often able to skip many of the steps that lead up to this point in my story where Herceptin is introduced. Many now receive it in combination with Taxol as their first line treatment with phenomenal results, and they avoid many of the harsh side effects of the older treatment protocols that I had to endure before receiving Herceptin. This is an amazing change in the landscape of breast cancer treatment from my perspective.



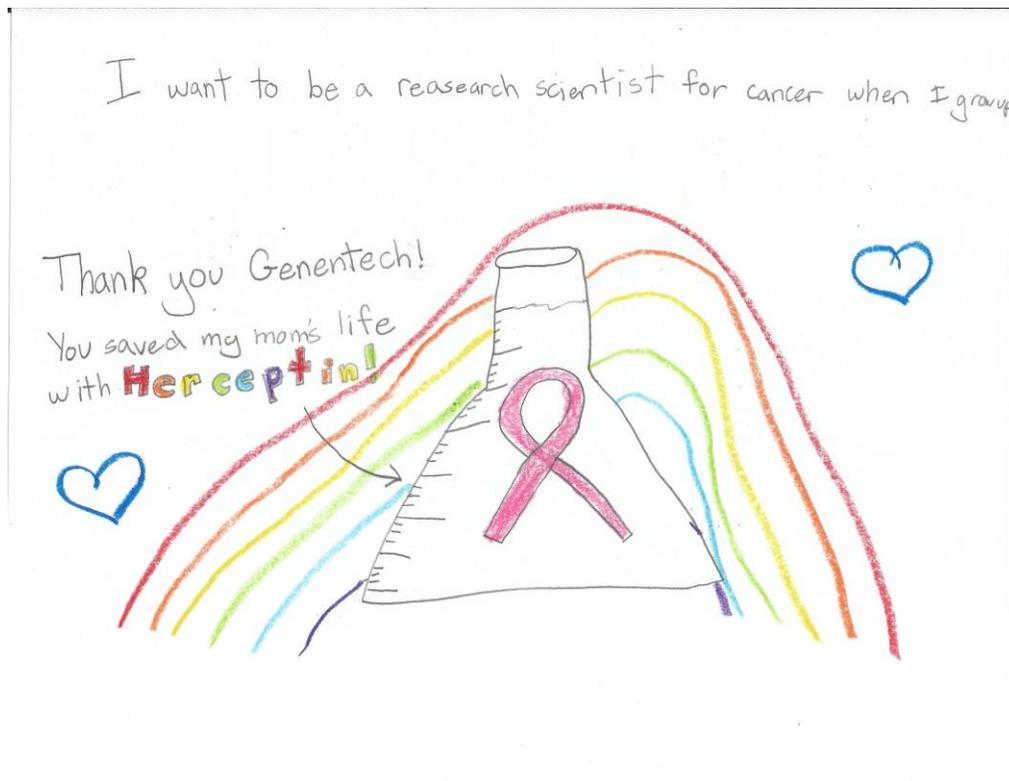
Herceptin proves to be a dream compared to all the other treatments that have been done to me. It's brilliant, 21st century medicine that marks and removes the bad cells while leaving the good. How lucky am I to live in a time where such a thing exists!?? I welcome every two week appointment, when the clear liquid drips down the line and into my chest port; I'm deeply thankful to all the women who have come before me who were willing to be part of the clinical trials, who were willing to say, "I want so much to live," so that others who came after them might benefit from their sacrifice. I know this is the thing that will save my life because *nothing* else up to this point seems to have turned the tide. My body heals slowly but surely over the course of a year, and Herceptin is my golden ticket, my life line, my 50% increased chance to win this awful hand I've been dealt.



And through it all, I attend my Young Survivors peer support group meetings and hold space for others going through this so-called journey. The leader gets diagnosed with mets and moves to California, the founder gets a recurrence and dies of metastatic breast cancer, leaving twin four year old daughters motherless. I felt called to take on the responsibility of caring for the young women facing this disease in the Portland metro area, and for the last few years I have led the group as it continues to grow in a way that is bittersweet. I wish that there weren't still so many women facing breast cancer when they should be enjoying their 20s, 30s, and 40s. It's the group no one *wants* to belong to, but we are here for each other, continuing to reach back through the fire to help our sisters through to the other side, to wholeness, to healing.

After five years of living with an unreconstructed chest and finding no mastectomy bra that was comfortable or that would suit my active, mom-on-the-go lifestyle, I was introduced to the Handful Bra by a neighbor. It proved to be a life-changing event. I put on the bra and stuffed three Handful Pads on each side, and suddenly, I felt whole again. While breasts or lack thereof *don't* define me, having something to fill out a top just makes me feel better, look better, and perform better. A good foundation garment also helped my posture, which was slowly but surely collapsing inward as I unconsciously hunched to hide what was missing from my chest. My endocrinologist follows me closely due to osteoporosis from all the treatments I've had that have negatively impacted my bone health, and she was shocked to find out I gained a half inch back in height!

The only explanation we could come up with for this was six months of consistently wearing and working out in the Handful Bra and noting how it makes me stand up straighter, throw my shoulders back and walk with pride. I believe in this bra and this women-run company so much that I went to work for Handful last October, helping to educate the mastectomy market on the need to carry an option for a new generation of modern, active survivors who want to get back to the business of living life to the fullest in a bra that supports women, no matter what life throws their way.



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