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# Our Feel-Good War on Breast Cancer

By PEGGY ORENSTEIN

I used to believe that a mammogram saved my life. I even wrote that in the pages of this magazine. It was 1996, and I had just turned 35 when my doctor sent me for an initial screening — a relatively common practice at the time — that would serve as a base line when I began annual mammograms at 40. I had no family history of breast cancer, no particular risk factors for the disease.

So when the radiologist found an odd, bicycle-spoke-like pattern on the film — not even a lump — and sent me for a biopsy, I wasn't worried. After all, who got breast cancer at 35?

It turns out I did. Recalling the fear, confusion, anger and grief of that time is still painful. My only solace was that the system worked precisely as it should: the mammogram caught my tumor early, and I was treated with a lumpectomy and six weeks of radiation; I was going to survive.

By coincidence, just a week after my diagnosis, a panel convened by the National Institutes of Health made headlines when it declined to recommend universal screening for women in their 40s; evidence simply didn't show it significantly decreased breast-cancer deaths in that age group. What's more, because of their denser breast tissue, younger women were subject to disproportionate false positives — leading to unnecessary biopsies and worry — as well as false negatives, in which cancer was missed entirely.

Those conclusions hit me like a sucker punch. "I am the person whose life is officially not worth saving," I wrote angrily. When the American Cancer Society as well as the newer Susan G. Komen foundation rejected the panel's findings, saying mammography was still the best tool to decrease breast-cancer mortality, friends across the country called to congratulate me as if I'd scored a personal victory. I considered myself a loud-and-proud example of the benefits of early detection.

Sixteen years later, my thinking has changed. As study after study revealed the limits of screening — and the dangers of overtreatment — a thought niggled at my consciousness. How much had my mammogram really mattered? Would the outcome have been the same had I bumped into the cancer on my own years later? It's hard to argue with a good result. After all, I am alive and grateful to be here. But I've watched friends whose breast cancers

were detected “early” die anyway. I’ve sweated out what blessedly turned out to be false alarms with many others.

Recently, a survey of three decades of screening published in November in *The New England Journal of Medicine* found that mammography’s impact is decidedly mixed: it does reduce, by a small percentage, the number of women who are told they have late-stage cancer, but it is far more likely to result in overdiagnosis and unnecessary treatment, including surgery, weeks of radiation and potentially toxic drugs. And yet, mammography remains an unquestioned pillar of the pink-ribbon awareness movement. Just about everywhere I go — the supermarket, the dry cleaner, the gym, the gas pump, the movie theater, the airport, the florist, the bank, the mall — I see posters proclaiming that “early detection is the best protection” and “mammograms save lives.” But how many lives, exactly, are being “saved,” under what circumstances and at what cost? Raising the public profile of breast cancer, a disease once spoken of only in whispers, was at one time critically important, as was emphasizing the benefits of screening. But there are unintended consequences to ever-greater “awareness” — and they, too, affect women’s health.

**Breast cancer in** your breast doesn’t kill you; the disease becomes deadly when it metastasizes, spreading to other organs or the bones. Early detection is based on the theory, dating back to the late 19th century, that the disease progresses consistently, beginning with a single rogue cell, growing sequentially and at some invariable point making a lethal leap. Curing it, then, was assumed to be a matter of finding and cutting out a tumor before that metastasis happens.

The thing is, there was no evidence that the size of a tumor necessarily predicted whether it had spread. According to Robert Aronowitz, a professor of history and sociology of science at the University of Pennsylvania and the author of “Unnatural History: Breast Cancer and American Society,” physicians endorsed the idea anyway, partly out of wishful thinking, desperate to “do something” to stop a scourge against which they felt helpless. So in 1913, a group of them banded together, forming an organization (which eventually became the American Cancer Society) and alerting women, in a precursor of today’s mammography campaigns, that surviving cancer was within their power. By the late 1930s, they had mobilized a successful “Women’s Field Army” of more than 100,000 volunteers, dressed in khaki, who went door to door raising money for “the cause” and educating neighbors to seek immediate medical attention for “suspicious symptoms,” like lumps or irregular bleeding.

The campaign worked — sort of. More people did subsequently go to their doctors. More cancers were detected, more operations were performed and more patients survived their initial treatments. But the rates of women dying of breast cancer hardly budged. All those

increased diagnoses were not translating into “saved lives.” That should have been a sign that some aspect of the early-detection theory was amiss. Instead, surgeons believed they just needed to find the disease even sooner.

Mammography promised to do just that. The first trials, begun in 1963, found that screening healthy women along with giving them clinical exams reduced breast-cancer death rates by about 25 percent. Although the decrease was almost entirely among women in their 50s, it seemed only logical that, eventually, screening younger (that is, finding cancer earlier) would yield even more impressive results. Cancer might even be cured.

That hopeful scenario could be realized, though, if women underwent annual mammography, and by the early 1980s, it is estimated that fewer than 20 percent of those eligible did. Nancy Brinker founded the Komen foundation in 1982 to boost those numbers, convinced that early detection and awareness of breast cancer could have saved her sister, Susan, who died of the disease at 36. Three years later, National Breast Cancer Awareness Month was born. The khaki-clad “soldiers” of the 1930s were soon displaced by millions of pink-garbed racers “for the cure” as well as legions of pink consumer products: pink buckets of chicken, pink yogurt lids, pink vacuum cleaners, pink dog leashes. Yet the message was essentially the same: breast cancer was a fearsome fate, but the good news was that through vigilance and early detection, surviving was within their control.

By the turn of the new century, the pink ribbon was inescapable, and about 70 percent of women over 40 were undergoing screening. The annual mammogram had become a near-sacred rite, so precious that in 2009, when another federally financed independent task force reiterated that for most women, screening should be started at age 50 and conducted every two years, the reaction was not relief but fury. After years of bombardment by early-detection campaigns (consider: “If you haven’t had a mammogram, you need more than your breasts examined”), women, surveys showed, seemed to think screening didn’t just find breast cancer but actually prevented it.

At the time, the debate in Congress over health care reform was at its peak. Rather than engaging in discussion about how to maximize the benefits of screening while minimizing its harms, Republicans seized on the panel’s recommendations as an attempt at health care rationing. The Obama administration was accused of indifference to the lives of America’s mothers, daughters, sisters and wives. Secretary Kathleen Sebelius of the Department of Health and Human Services immediately backpedaled, issuing a statement that the administration’s policies on screening “remain unchanged.”

**Even as American women** embraced mammography, researchers' understanding of breast cancer — including the role of early detection — was shifting. The disease, it has become clear, does not always behave in a uniform way. It's not even one disease. There are at least four genetically distinct breast cancers. They may have different causes and definitely respond differently to treatment. Two related subtypes, luminal A and luminal B, involve tumors that feed on estrogen; they may respond to a five-year course of pills like tamoxifen or aromatase inhibitors, which block cells' access to that hormone or reduce its levels. In addition, a third type of cancer, called HER2-positive, produces too much of a protein called human epidermal growth factor receptor 2; it may be treatable with a targeted immunotherapy called Herceptin. The final type, basal-like cancer (often called "triple negative" because its growth is not fueled by the most common biomarkers for breast cancer — estrogen, progesterone and HER2), is the most aggressive, accounting for up to 20 percent of breast cancers. More prevalent among young and African-American women, it is genetically closer to ovarian cancer. Within those classifications, there are, doubtless, further distinctions, subtypes that may someday yield a wider variety of drugs that can isolate specific tumor characteristics, allowing for more effective treatment. But that is still years away.

Those early mammography trials were conducted before variations in cancer were recognized — before Herceptin, before hormonal therapy, even before the widespread use of chemotherapy. Improved treatment has offset some of the advantage of screening, though how much remains contentious. There has been about a 25 percent drop in breast-cancer death rates since 1990, and some researchers argue that treatment — not mammograms — may be chiefly responsible for that decline. They point to a study of three pairs of European countries with similar health care services and levels of risk: In each pair, mammograms were introduced in one country 10 to 15 years earlier than in the other. Yet the mortality data are virtually identical. Mammography didn't seem to affect outcomes. In the United States, some researchers credit screening with a death-rate reduction of 15 percent — which holds steady even when screening is reduced to every other year. Gilbert Welch, a professor of medicine at the Dartmouth Institute for Health Policy and Clinical Practice and co-author of last November's New England Journal of Medicine study of screening-induced overtreatment, estimates that only 3 to 13 percent of women whose cancer was detected by mammograms actually benefited from the test.

If Welch is right, the test helps between 4,000 and 18,000 women annually. Not an insignificant number, particularly if one of them is you, yet perhaps less than expected given the 138,000 whose cancer has been diagnosed each year through screening. Why didn't early detection work for more of them? Mammograms, it turns out, are not so great at detecting

the most lethal forms of disease — like triple negative — at a treatable phase. Aggressive tumors progress too quickly, often cropping up between mammograms. Even catching them “early,” while they are still small, can be too late: they have already metastasized. That may explain why there has been no decrease in the incidence of metastatic cancer since the introduction of screening.

At the other end of the spectrum, mammography readily finds tumors that could be equally treatable if found later by a woman or her doctor; it also finds those that are so slow-moving they might never metastasize. As improbable as it sounds, studies have suggested that about a quarter of screening-detected cancers might have gone away on their own. For an individual woman in her 50s, then, annual mammograms may catch breast cancer, but they reduce the risk of dying of the disease over the next 10 years by only .07 percentage points — from .53 percent to .46 percent. Reductions for women in their 40s are even smaller, from .35 percent to .3 percent.

If screening’s benefits have been overstated, its potential harms are little discussed. According to a survey of randomized clinical trials involving 600,000 women around the world, for every 2,000 women screened annually over 10 years, one life is prolonged but 10 healthy women are given diagnoses of breast cancer and unnecessarily treated, often with therapies that themselves have life-threatening side effects. (Tamoxifen, for instance, carries small risks of stroke, blood clots and uterine cancer; radiation and chemotherapy weaken the heart; surgery, of course, has its hazards.)

Many of those women are told they have something called ductal carcinoma in situ (D.C.I.S.), or “Stage Zero” cancer, in which abnormal cells are found in the lining of the milk-producing ducts. Before universal screening, D.C.I.S. was rare. Now D.C.I.S. and the less common lobular carcinoma in situ account for about a quarter of new breast-cancer cases — some 60,000 a year. In situ cancers are more prevalent among women in their 40s. By 2020, according to the National Institutes of Health’s estimate, more than one million American women will be living with a D.C.I.S. diagnosis.

D.C.I.S. survivors are celebrated at pink-ribbon events as triumphs of early detection: theirs was an easily treatable disease with a nearly 100 percent 10-year survival rate. The thing is, in most cases (estimates vary widely between 50 and 80 percent) D.C.I.S. will stay right where it is — “in situ” means “in place.” Unless it develops into invasive cancer, D.C.I.S. lacks the capacity to spread beyond the breast, so it will not become lethal. Autopsies have shown that as many as 14 percent of women who died of something other than breast cancer unknowingly had D.C.I.S.

There is as yet no sure way to tell which D.C.I.S. will turn into invasive cancer, so every instance is treated as if it is potentially life-threatening. That needs to change, according to Laura Esserman, director of the Carol Franc Buck Breast Care Center at the University of California, San Francisco. Esserman is campaigning to rename D.C.I.S. by removing its big “C” in an attempt to put it in perspective and tamp down women’s fear. “D.C.I.S. is not cancer,” she explained. “It’s a *risk factor*. For many D.C.I.S. lesions, there is only a 5 percent chance of invasive cancer developing over 10 years. That’s like the average risk of a 62-year-old. We don’t do heart surgery when someone comes in with high cholesterol. What are we doing to these people?” In Britain, where women are screened every three years beginning at 50, the government recently decided to revise its brochure on mammography to include a more thorough discussion of overdiagnosis, something it previously dispatched with in one sentence. That may or may not change anyone’s mind about screening, but at least there is a fuller explanation of the trade-offs.

In this country, the huge jump in D.C.I.S. diagnoses potentially transforms some 50,000 healthy people a year into “cancer survivors ” and contributes to the larger sense that breast cancer is “everywhere,” happening to “everyone.” That, in turn, stokes women’s anxiety about their personal vulnerability, increasing demand for screening — which, inevitably, results in even more diagnoses of D.C.I.S. Meanwhile, D.C.I.S. patients themselves are subject to the pain, mutilation, side effects and psychological trauma of anyone with cancer and may never think of themselves as fully healthy again.

Yet who among them would dare do things differently? Which of them would have skipped that fateful mammogram? As Robert Aronowitz, the medical historian, told me: “When you’ve oversold both the fear of cancer and the effectiveness of our prevention and treatment, even people harmed by the system will uphold it, saying, ‘It’s the only ritual we have, the only thing we can do to prevent ourselves from getting cancer.’ ”

What if I had skipped my first mammogram and found my tumor a few years later in the shower? It’s possible that by then I would have needed chemotherapy, an experience I’m profoundly thankful to have missed. Would waiting have affected my survival? Probably not, but I’ll never know for sure; no woman truly can. Either way, the odds were in my favor: my good fortune was not just that my cancer was caught early but also that it appeared to have been treatable.

Note that word “appeared”: one of breast cancer’s nastier traits is that even the lowest-grade caught-it-early variety can recur years — decades — after treatment. And mine did.

**Last summer**, nine months after my most recent mammogram, while I was getting ready for bed and chatting with my husband, my fingers grazed something small and firm beneath the scar on my left breast. Just like that, I passed again through the invisible membrane that separates the healthy from the ill.

This latest tumor was as tiny and as pokey as before, unlikely to have spread. Obviously, though, it had to go. Since a lumpectomy requires radiation, and you can't irradiate the same body part twice, my only option this round was a mastectomy. I was also prescribed tamoxifen to cut my risk of metastatic disease from 20 percent to 12. Again, that means I should survive, but there are no guarantees; I won't know for sure whether I am cured until I die of something else — hopefully many decades from now, in my sleep, holding my husband's hand, after a nice dinner with the grandchildren.

My first instinct this round was to have my other breast removed as well — I never wanted to go through this again. My oncologist argued against it. The tamoxifen would lower my risk of future disease to that of an average woman, he said. Would an average woman cut off her breasts? I could have preventive surgery if I wanted to, he added, but it would be a psychological decision, not a medical one.

I weighed the options as my hospital date approached. Average risk, after all, is not zero. Could I live with that? Part of me still wanted to extinguish all threat. I have a 9-year-old daughter; I would do anything — I need to do *everything* — to keep from dying. Yet, if death was the issue, the greatest danger wasn't my other breast. It is that, despite treatment and a good prognosis, the cancer I've already had has metastasized. Preventive mastectomy wouldn't change that; nor would it entirely eliminate the possibility of new disease, because there's always some tissue left behind.

What did doing "everything" mean, anyway? There are days when I skip sunscreen. I don't exercise as much as I should. I haven't given up aged Gouda despite my latest cholesterol count; I don't get enough calcium. And, oh, yeah, my house is six blocks from a fault line. Is living with a certain amount of breast-cancer risk really so different? I decided to take my doctor's advice, to do only what had to be done.

I assumed my dilemma was unusual, specific to the anxiety of having been too often on the wrong side of statistics. But it turned out that thousands of women now consider double mastectomies after low-grade cancer diagnoses. According to Todd Tuttle, chief of the division of surgical oncology at the University of Minnesota and lead author of a study on prophylactic mastectomy published in *The Journal of Clinical Oncology*, there was a 188 percent jump between 1998 and 2005 among women given new diagnoses of D.C.I.S. in one

breast — a risk factor for cancer — who opted to have both breasts removed just in case. Among women with early-stage invasive disease (like mine), the rates rose about 150 percent. Most of those women did not have a genetic predisposition to cancer. Tuttle speculated they were basing their decisions not on medical advice but on an exaggerated sense of their risk of getting a new cancer in the other breast. Women, according to another study, believed that risk to be more than 30 percent over 10 years when it was actually closer to 5 percent.

It wasn't so long ago that women fought to keep their breasts after a cancer diagnosis, lobbying surgeons to forgo radical mastectomies for equally effective lumpectomies with radiation. Why had that flipped? I pondered the question as I browsed through the "Stories of Hope" on the American Cancer Society's Web site. I came across an appealing woman in a pink T-shirt, smiling as she held out a white-frosted cupcake bedecked with a pink candle. In a first-person narrative, she said that she began screening in her mid-30s because she had fibrocystic breast disease. At 41, she was given a diagnosis of D.C.I.S., which was treated with lumpectomy and radiation. "I felt lucky to have caught it early," she said, though she added that she was emotionally devastated by the experience. She continued screenings and went on to have multiple operations to remove benign cysts. By the time she learned she had breast cancer again, she was looking at a fifth operation on her breasts. So she opted to have both of them removed, a decision she said she believed to be both logical and proactive.

I found myself thinking of an alternative way to describe what happened. Fibrocystic breast disease does not predict cancer, though distinguishing between benign and malignant tumors can be difficult, increasing the potential for unnecessary biopsies. Starting screening in her 30s exposed this woman to years of excess medical radiation — one of the few known causes of breast cancer. Her D.C.I.S., a condition detected almost exclusively through mammography, quite likely never would become life-threatening, yet it transformed her into a cancer survivor, subjecting her to surgery and weeks of even more radiation. By the time of her second diagnosis, she was so distraught that she amputated both of her breasts to restore a sense of control.

Should this woman be hailed as a survivor or held up as a cautionary tale? Was she empowered by awareness or victimized by it? The fear of cancer is legitimate: how we manage that fear, I realized — our responses to it, our emotions around it — can be manipulated, packaged, marketed and sold, sometimes by the very forces that claim to support us. That can color everything from our perceptions of screening to our understanding of personal risk to our choices in treatment. "You could attribute the rise in mastectomies to a better understanding of genetics or better reconstruction techniques," Tuttle said, "but those are available in Europe, and you don't see that mastectomy craze

there. There is so much ‘awareness’ about breast cancer in the U.S. I’ve called it breast-cancer overawareness. It’s everywhere. There are pink garbage trucks. Women are petrified.”

“**Nearly 40,000 women** and 400 men die every year of breast cancer,” Lynn Erdman, vice president of community health at Komen, told me. “Until that number dissipates, we don’t think there’s enough pink.”

I was sitting in a conference room at the headquarters of Susan G. Komen, near the Galleria mall in Dallas. Komen is not the country’s largest cancer charity — that would be the American Cancer Society. It is, however, the largest breast-cancer organization. And although Komen’s image was tarnished last year by its attempt to defund a Planned Parenthood screening program, its name remains virtually synonymous with breast-cancer advocacy. With its dozens of races “for the cure” and some 200 corporate partnerships, it may be the most successful charity ever at branding a disease; its relentless marketing has made the pink ribbon one of the most recognized logos of our time. The ribbon has come to symbolize both fear of the disease and the hope it can be defeated. It’s a badge of courage for the afflicted, an expression of solidarity by the concerned. It promises continual progress toward a cure through donations, races, volunteerism. It indicates community. And it offers corporations a seemingly fail-safe way to signal good will toward women, even if, in a practice critics call “pinkwashing,” the products they produce are linked to the disease or other threats to public health. Having football teams don rose-colored cleats, for instance, can counteract bad press over how the N.F.L. handles accusations against players of rape or domestic violence. Chevron’s donations to California Komen affiliates may help deflect what Cal OSHA called its “willful violations” of safety that led to a huge refinery fire last year in a Bay Area neighborhood.

More than anything else, though, the ribbon reminds women that every single one of us is vulnerable to breast cancer, and our best protection is annual screening. Despite the fact that Komen trademarked the phrase “for the cure,” only 16 percent of the \$472 million raised in 2011, the most recent year for which financial reports are available, went toward research. At \$75 million, that’s still enough to give credence to the claim that Komen has been involved in every major breast-cancer breakthrough for the past 29 years. Still, the sum is dwarfed by the \$231 million the foundation spent on education and screening.

Though Komen now acknowledges the debate over screening on its Web site, the foundation has been repeatedly accused of overstating mammography’s benefits while dismissing its risks. Steve Woloshin, a colleague of Welch’s at Dartmouth and [co-author of the Not So Stories column in The British Medical Journal](#), points to a recent Komen print ad that reads: “The five-year survival rate for breast cancer when caught early is 98 percent. When it’s not?”

It decreases to 23 percent.” Woloshin called that willfully deceptive. The numbers are accurate, but five-year survival rates are a misleading measure of success, skewed by screening itself. Mammography finds many cancers that never need treating and that are, by definition, survivable. Meanwhile, some women with lethal disease may *seem* to live longer because their cancer was found earlier, but in truth, it’s only their awareness of themselves as ill that has been extended. “Imagine a group of 100 women who received diagnoses of breast cancer because they felt a breast lump at age 67, all of whom die at age 70,” Woloshin said. “Five-year survival for this group is 0 percent. Now imagine the same women were screened, given their diagnosis three years earlier, at age 64, but treatment doesn’t work and they still die at age 70. Five-year survival is now 100 percent, even though no one lived a second longer.”

When I asked Chandini Portteus, vice president of research, evaluation and scientific programs at Komen, in January why the foundation continued to use that statistic, she didn’t so much explain as sidestep. “I don’t think Komen meant to mislead,” she said. “We know that mammography certainly isn’t perfect. We also know that it’s what we have and that it’s important in diagnosing breast cancer.” (The statistic was subsequently removed from its Web site.)

In “Pink Ribbon Blues,” Gayle Sulik, a sociologist and founder of the Breast Cancer Consortium, credits Komen (as well as the American Cancer Society and National Breast Cancer Awareness Month) with raising the profile of the disease, encouraging women to speak about their experience and transforming “victims” into “survivors.” Komen, she said, has also distributed more than \$1 billion to research and support programs. At the same time, the function of pink-ribbon culture — and Komen in particular — has become less about eradication of breast cancer than self-perpetuation: maintaining the visibility of the disease and keeping the funds rolling in. “You have to look at the agenda for each program involved,” Sulik said. “If the goal is eradication of breast cancer, how close are we to that? Not very close at all. If the agenda is awareness, what is it making us aware of? That breast cancer exists? That it’s important? ‘Awareness’ has become narrowed until it just means ‘visibility.’ And that’s where the movement has failed. That’s where it’s lost its momentum to move further.”

Before the pink ribbon, awareness as an end in itself was not the default goal for health-related causes. Now you’d be hard-pressed to find a major illness without a logo, a wearable ornament and a roster of consumer-product tie-ins. Heart disease has its red dress, testicular cancer its yellow bracelet. During “Movember” — a portmanteau of “mustache” and “November” — men are urged to grow their facial hair to “spark conversation and raise awareness” of prostate cancer (another illness for which early detection has led to large-scale

overtreatment) and testicular cancer. “These campaigns all have a similar superficiality in terms of the response they require from the public,” said Samantha King, associate professor of kinesiology and health at Queen’s University in Ontario and author of “Pink Ribbons, Inc.” “They’re divorced from any critique of health care policy or the politics of funding biomedical research. They reinforce a single-issue competitive model of fund-raising. And they whitewash illness: we’re made ‘aware’ of a disease yet totally removed from the challenging and often devastating realities of its sufferers.”

I recalled the dozens of news releases I received during last October’s National Breast Cancer Awareness Month, an occasion I observed in bed while recovering from my mastectomy. There was the one from Komen urging me to make a “curemitment” to ending breast cancer by sharing a “message about early detection or breast self-awareness that resonates with you”; the one about the town painting itself pink for “awareness”; the one from a Web site called Pornhub that would donate a penny to a breast-cancer charity for every 30 views of its “big-” or “small-breast” videos.

Then there are the groups going after the new hot “awareness” demographic: young women. “Barbells for Boobies” was sponsoring weight-lifting fund-raisers to pay for mammograms for women under 40. Keep A Breast (known for its sassy “I ♥ Boobies” bracelets) urges girls to perform monthly self-exams as soon as they begin menstruating. Though comparatively small, these charities raise millions of dollars a year — Keep A Breast alone raised \$3.6 million in 2011. Such campaigns are often inspired by the same heartfelt impulse that motivated Nancy Brinker to start Komen: the belief that early detection could have saved a loved one, the desire to make meaning of a tragedy.

Yet there’s no reason for anyone — let alone young girls — to perform monthly self-exams. Many breast-cancer organizations stopped pushing it more than a decade ago, when a 12-year randomized study involving more than 266,000 Chinese women, published in *The Journal of the National Cancer Institute*, found no difference in the number of cancers discovered, the stage of disease or mortality rates between women who were given intensive instruction in monthly self-exams and women who were not, though the former group was subject to more biopsies. The upside was that women were pretty good at finding their own cancers either way.

Beyond misinformation and squandered millions, I wondered about the wisdom of educating girls to be aware of their breasts as precancerous organs. If decades of pink-ribboned early-detection campaigns have distorted the fears of middle-aged women, exaggerated their sense of personal risk, encouraged extreme responses to even low-level

diagnoses, all without significantly changing outcomes, what will it mean to direct that message to a school-aged crowd?

Young women do get breast cancer — I was one of them. Even so, breast cancer among the young, especially the very young, is rare. The median age of diagnosis in this country is 61. The median age of death is 68. The chances of a 20-year-old woman getting breast cancer in the next 10 years is about .06 percent, roughly the same as for a man in his 70s. And no one is telling him to “check your boobies.”

“It’s tricky,” said Susan Love, a breast surgeon and president of the Dr. Susan Love Research Foundation. “Some young women get breast cancer, and you don’t want them to ignore it, but educating kids earlier — that bothers me. Here you are, especially in high school or junior high, just getting to know to your body. To do this search-and-destroy mission where your job is to find cancer that’s lurking even though the chance is minuscule to none. . . . It doesn’t serve anyone. And I don’t think it empowers girls. It scares them.”

Rather than offering blanket assurances that “mammograms save lives,” advocacy groups might try a more realistic campaign tag line. The researcher Gilbert Welch has suggested, “Mammography has both benefits and harms — that’s why it’s a personal decision.” That was also the message of the 2009 task force, which was derailed by politics: scientific evidence indicates that getting mammograms every other year if you are between the ages of 50 and 74 makes sense; if you fall outside that age group and still want to be screened, you should be fully informed of the downsides.

**Women are now** well aware of breast cancer. So what’s next? Eradicating the disease (or at least substantially reducing its incidence and devastation) may be less a matter of raising more money than allocating it more wisely. When I asked scientists and advocates how at least some of that awareness money could be spent differently, their answers were broad and varied. Many brought up the meager funding for work on prevention. In February, for instance, a Congressional panel made up of advocates, scientists and government officials called for increasing the share of resources spent studying environmental links to breast cancer. They defined the term liberally to include behaviors like alcohol consumption, exposure to chemicals, radiation and socioeconomic disparities.

Other researchers are excited about the prospect of fighting or preventing cancer by changing the “microenvironment” of the breast — the tissue surrounding a tumor that can stimulate or halt its growth. Susan Love likened it to the way living in a good or bad neighborhood might sway a potentially delinquent child. “It may well be,” she told me, “that by altering the ‘neighborhood,’ whether it’s the immune system or the local tissue, we can

control or kill the cancer cells.” Taking hormone-replacement therapy during menopause, which was found to contribute to escalating rates of breast cancer, may have been the biological equivalent of letting meth dealers colonize a street corner. On the other hand, a vaccine, the current focus of some scientists and advocates, would be like putting more cops on the beat.

Nearly everyone agrees there is significant work to be done at both ends of the diagnostic spectrum: distinguishing which D.C.I.S. lesions will progress to invasive disease as well as figuring out the mechanisms of metastasis. According to a Fortune magazine analysis, only an estimated .5 percent of all National Cancer Institute grants since 1972 focus on metastasis; out of more than \$2.2 billion dollars raised over the last six years, Komen has dedicated \$79 million to such research — a lot of money, to be sure, but a mere 3.6 percent of its total budget during that period.

“A lot of people are under the notion that metastatic work is a waste of time,” said Danny Welch, chairman of the department of cancer biology at the University of Kansas Cancer Center, “because all we have to do is prevent cancer in the first place. The problem is, we still don’t even know what causes cancer. I’d prefer to prevent it completely too, but to put it crassly, that’s throwing a bunch of people under the bus right now.”

One hundred and eight American women die of breast cancer each day. Some can live for a decade or more with metastatic disease, but the median life span is 26 months. One afternoon I talked to Ann Silberman, author of the blog “[Breast Cancer? But Doctor . . . I Hate Pink.](#)” Silberman started writing it in 2009, at age 51, after finding a lump in her breast that turned out to be cancer — a Stage 2 tumor, which she was told gave her a survival rate of 70 percent. At the time she was a secretary at a school in Sacramento, happily married and the mother of two boys, ages 12 and 22. Over the next two years, she had surgery, did six rounds of chemo, took a trio of drugs including Herceptin and, finally, thought she was done.

Four months later, a backache and bloated belly sent her to the doctor; the cancer had spread to her liver. Why didn’t the treatment work? No one knows. “At this point, you know that you’re going to die, and you know it’s going to be in the next five years,” she told me. Her goal is to see her youngest son graduate from high school next June.

It isn’t easy to face someone with metastatic disease, especially if you’ve had cancer yourself. Silberman’s trajectory is my worst fear; the night after we spoke, I was haunted by dreams of cancer’s return. Perhaps for that reason, metastatic patients are notably absent from pink-ribbon campaigns, rarely on the speaker’s podium at fund-raisers or races. Last October, for

the first time, Komen featured a woman with Stage 4 disease in its awareness-month ads, but the wording carefully emphasized the positive: “Although, today, she has tumors in her bones, her liver and her lungs, Bridget still has hope.” (Bridget died earlier this month.)

“All that awareness terminology isn’t about us,” Silberman said. “It’s about surviving, and we’re not going to survive. We’re going to get sick. We’re going to lose parts of our livers. We’re going to be on oxygen. We’re going to die. It’s not pretty, and it’s not hopeful. People want to believe in ‘the cure,’ and they want to believe that cure is early detection. But you know what? It’s just not true.”

Scientific progress is erratic, unpredictable. “We are all foundering around in the dark,” said Peter B. Bach, director of the Center for Health Policy and Outcomes at Memorial Sloan-Kettering Cancer Center. “The one thing I can tell you is some of that foundering has borne fruit.” There are the few therapies, he said — like tamoxifen and Herceptin — that target specific tumor characteristics, and newer tests that estimate the chance of recurrence in estrogen-positive cancers, allowing lower-risk women to skip chemotherapy. “That’s not curing cancer,” Bach said, “but it’s progress. And yes, it’s slow.”

The idea that there could be one solution to breast cancer — screening, early detection, some universal cure — is certainly appealing. All of us — those who fear the disease, those who live with it, our friends and families, the corporations who swathe themselves in pink — wish it were true. Wearing a bracelet, sporting a ribbon, running a race or buying a pink blender expresses our hopes, and that feels good, even virtuous. But making a difference is more complicated than that.

It has been four decades since the former first lady Betty Ford went public with her breast-cancer diagnosis, shattering the stigma of the disease. It has been three decades since the founding of Komen. Two decades since the introduction of the pink ribbon. Yet all that well-meaning awareness has ultimately made women *less* conscious of the facts: obscuring the limits of screening, conflating risk with disease, compromising our decisions about health care, celebrating “cancer survivors” who may have never required treating. And ultimately, it has come at the expense of those whose lives are most at risk.

*Peggy Orenstein is a contributing writer for the magazine and the author, most recently, of “Cinderella Ate My Daughter: Dispatches From the Front Lines of the New Girlie-Girl Culture.”*

*Editor: Ilena Silverman*

*This article has been revised to reflect the following correction:*

***Correction: April 28, 2013***

*An article on Page 36 this weekend about breast cancer awareness misidentifies the reduction in the chance that a woman in her 50s will die of breast cancer over the next 10 years if she undergoes screening. It is .07 percentage points, not .07 percent.*