



## From the Executive Director: Breast cancer mammograms: overrated – and over-diagnosing women

*[Editor's Note: You may have seen Karuna's article back in April of this year when it was published in [The Guardian](#). The piece generated a lot of discussion – over 1,000 people shared it on their Facebook page and over 150 people commented on the article itself. Many of you who have been through several iterations of these debates are used to the controversy that arises from publically challenging routine mammography screening. What's new this time around is the growing agreement that the benefits of routine mammography screening have long been overstated, and the harms long underestimated. Ten years ago, our challenge to the conventional position that "early detection saves lives" and "early detection is your best protection" was highly unpopular. Our independent position was a hard truth for many to hear even though it was grounded in evidence because it went against the grain of pretty much every mainstream breast cancer organization—many of which were and still are heavily invested (both in terms of funders and core values) in the "early detection saves lives" philosophy. We've reached a tipping point recently and now increasingly we hear more discussion about this issue and less unquestioned acceptance of the earlier screening messages.]*

*By Karuna Jaggur, Executive Director*

How will we ever hope to make desperately needed progress in the breast cancer epidemic when the mainstream breast cancer movement continues to push an outdated and scientifically debunked agenda? The evidence has been mounting that the time has come to radically re-think the tenets of the breast cancer awareness movement because it is clear that the fundamental philosophy behind "early detection" is flawed.



I would hope, as I'm sure you do, that our country's leading cancer organizations with piles of money and clout would be the first to follow the science and put people's health before vested industry interests. But unfortunately I see that even powerful evidence cannot overcome the vested interests of many of the largest cancer organizations in the country – nonprofits like the American Cancer Society (ACS) and Susan G. Komen – which continue to push screening mammograms without caution.

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Last month, [the New England Journal of Medicine \(NEJM\) published](#) a strongly-worded perspective from the Swiss Medical Board concluding that mammography screening is "hard to justify". It followed the February publication of the largest study on mammography to date [in the British Medical Journal](#), which reported that screening seemingly healthy women with mammography to find breast cancers – before they could be felt as a lump in the breast – did not lead to lower death rates for average-risk women in their 40s and 50s.

In assessing the role of population-based screening, this absence of benefit is only compounded by evidence of harm: 21.9% of breast cancers found through mammography screening represented over-diagnosis, according to the Swiss Medical Board. This means that one in five women who was told she had breast cancer after her mammogram received unnecessary treatment for cancer. The implication of these results is that [tens of thousands of women](#) in the US each year undergo surgery, radiation and chemotherapy for non-life threatening cancers.

Why, then, do mainstream cancer organizations, like ACS and Komen, continue to promise that "early detection saves lives" and "early detection is your best protection"? Their mantra has not changed despite the increasing certainty that such claims are inflated and imbalanced. If all of this sounds familiar to you, it's because evidence has been mounting for a long time that our best hope for ending the breast cancer epidemic does not, as we've been told for years through slick pink marketing campaigns, lie in mammograms.

The perspective published by the NEJM stems from an independent multidisciplinary panel's review of the data around mammography screening and concludes that "providing clear, unbiased information, promoting appropriate care, and preventing over-diagnosis and over-treatment would be a better choice [than promoting mammography screening programs]."

Yet the mainstream breast cancer movement, which is financed largely by pink ribbons and primarily focuses on early detection programs, has not responded with evidence-based changes to their positions and educational materials. The websites [for ACS](#) and [for Komen](#) continue to eagerly push screening mammograms for women age 40 and over without acknowledgment of the harms of screening programs. Indeed, the American Cancer Society offers to send women a "free breast cancer screening reminder" – and grow their own (monetizable) email list.

After years of pink-ribbon "awareness" campaigns, the NEJM study points out, many women in the US overestimate their personal risk of breast cancer. Furthermore, they vastly

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overestimate the benefit from mammograms. Women believe their risk of dying from breast cancer is double if they don't undergo regular mammography screening.

Yet the data show that there is no evidence that routine mammography screening for women at average risk actually saves lives.

At what point are we going to stop this madness, take stock of the science and acknowledge that widespread screening mammography for non-high risk women is not the answer to the breast cancer epidemic?

When are we going to hold our cancer charities to a higher standard – and hold them accountable for pushing a scientifically invalid message?

And are we ever going to question what we actually have to show for the billions of dollars spent on screening mammograms?

Despite leading the world in health spending, the U.S. notably lags in many health outcomes. As studies and analyses on mammography screening continue to cast doubt on this strategy, there is a growing trend in Europe to phase out population-based mammography screening for healthy women at average risk of breast cancer. Yet here in the U.S., mammography screening remains a foundation of the mainstream breast cancer movement, which has told us for more than 30 years that early detection is the solution to the breast cancer epidemic.

The evidence is in. We will never address and end the breast cancer epidemic simply through mammography screening. And the problem is not simply the tool (mammography) but the basic philosophy (early detection).

Our healthcare choices are driven by the expectation that they will improve and extend our lives – yet mammography screening does neither. Instead, widespread population-based screening has created a population of over-diagnosed breast cancer "survivors" without actually saving the lives of many of those same women.

As each woman evaluates her health decisions, we must ensure that we all have access to unbiased information, free from conflict of interest and without the heavy thumb of vested interests tipping the balance.

For more information, see our webinars and fact sheets on this issue at [www.bcaction.org](http://www.bcaction.org).

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## The Truth About Breast Cancer

The truth about breast cancer is never an easy story to tell because there is nothing comforting, secure, soft or reassuring about breast cancer.

The reality is doctor's visits, radiation appointments, chemo infusions and their aftermath. And there's always the uncertainty of recurrence. Many mainstream breast cancer organizations won't talk about these hard realities even though the women they serve live with them every day. We will not end the breast cancer epidemic unless we confront this disease in its entirety, hard truth and all. No matter how hard we hope and how many pretty pink ribbons we buy.



Breast Cancer Action is not like most mainstream breast cancer organizations. We aren't afraid to stand up and speak out about the uncomfortable realities of this disease and we don't cover up the hard issues with pretty pink ribbons.

In our new 5 minute video, BCAction member Emily Kaplan talks and candidly reveals the hard truths of breast cancer.

We hope you will watch the video and share it with your friends via email or on Facebook. You can view the video online at <http://bcaction.org/2014/06/24/how-hard-is-the-truth-to-watch/>.

## Program Highlights

### Latest News About Breast Cancer Screening Mammography

The evidence and recommendations about breast cancer screening mammography can feel confusing to many women. Over the past several months, we've published several pieces about mammography screening. We published a piece in the Huffington Post about the mounting evidence that mammography screening does not, in fact, "save lives" and our op-ed arguing for the radical re-thinking of the flawed philosophy behind the 'early detection' mantra that dominates the breast cancer awareness movement was published in The Guardian. In May, we hosted a webinar featuring Dr. Anthony B. Miller, Professor Emeritus of the University of Toronto's Dalla Lana School of Public Health and lead author of one of the largest studies on screening mammography to date, the Canadian National Breast Screening Study.

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### Addressing the Root Causes of Breast Cancer – and Pinkwashing

Currently, our work on primary prevention of breast cancer is centered on the regulation of toxic chemicals linked to breast cancer. Things definitely heated up this spring around reform of our broken and outdated chemical regulations.

One effort, the introduction of the Chemicals in Commerce Act (CICA) was an absolute gift to the chemical industry. CICA scales back the Environmental Protection Agency's (EPA) authority to regulate or require testing of new chemicals, allows companies to mask the identity of a chemical linked to toxic health effects, and could overrule stronger existing or future state chemical laws. Procter & Gamble, to name but one corporation, testified in favor of CICA. P&G also manufactures and markets products sporting pink ribbons during Breast Cancer Awareness month each October. Hmmm! Imagine that. A huge, highly profitable corporation that sells pink ribbon products supporting legislation that allows them to manufacture products that contain chemicals linked to an increased risk of the disease! We have a name for that—pinkwashing—and we aren't afraid to use it!

Speaking of huge, highly profitable corporations, Avon announced this spring that they'll remove a hazardous chemical, triclosan, from their line of cosmetics and personal care products. Hooray? Not so fast! While this announcement is certainly a step in the right direction, it is also too little, too late. And we wrote about why. Other huge corporations like Johnson & Johnson have already made similar and stronger commitments, eliminating triclosan as well as other chemicals of concern from their products as well.

### Walgreens: Mind the Store!

We helped tell Walgreens to Mind the Store by getting toxic products off their shelves.

In April, the Safer Chemicals, Healthy Families Coalition's Mind the Store campaign really got activists out on the streets. We're proud to be a member of this coalition, and here in San Francisco we paid a visit to our local downtown Walgreens for some good old-fashioned direct action demanding that Walgreens stop selling products that contain hazardous ingredients that threaten our health.



Also in April, we took action alongside communities in Wyoming, Texas and Pennsylvania whose water is contaminated with hazardous chemicals from nearby fracking operations.

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Along with anti-fracking activists from across the country, we're demanding that the EPA Administrator Gina McCarthy re-open their investigations into drinking water contamination – because everyone deserves non-toxic drinking water.

If you are interested in how researchers actually study environmental links to breast cancer and develop improved methods for identifying toxic chemicals and you weren't able to make our webinar in June with Ruthann Rudell from Silent Spring Institute and Megan Schwarzman at the University of California, Berkeley School of Public Health then catch up now by watching the webinar online [here](#).

### Community Leaders for Change

We welcomed two new members to our Community Leaders for Change program in the last few months, Jeanette Koncikowski from New York and Ilsa Flanagan from Illinois. For more information about the Community Leaders for Change program or to become a Community Leader, please contact Sahru Keiser at 415-243-9301 x14 or [skeiser@bcaction.org](mailto:skeiser@bcaction.org).

For more information on these topics and more, visit our blog at <http://bcaction.org/blog/>.

## **Book Review: *My Soul is Among Lions: Pages from the Breast Cancer Archives* by Ellen Leopold**

*By Angela Wall, BCAction Communications Director*

I have to begin with a disclaimer. Or two. Reading a book with a picture of former BCAction Executive Director [Barbara Brenner](#) front and center on the cover is obviously going to get my attention. And when the author happens to be a woman who has spent most of her life thinking, writing and speaking out about injustices in breast cancer, not to mention been a frequent contributor to *The Source*, I'm probably going to be a little biased in my review of the book. But even taking all that into account, when a book comes across your desk with the title *My Soul is Among Lions*, chances are it's going to be good. And this one did not disappoint.



Ellen Leopold's book [My Soul is Among Lions: Pages from the Breast Cancer Archives](#) (Valley Green Press, 2014) is remarkable. Not in the way a full moon is worth a mention but in the way small stars visible on a cloudless night cause you to pause and remember that there's so much more to the sky than the thing that's brightest, shiniest, and most visible. This book brings together many of Leopold's essays and, combined in this collection, they reveal a history of

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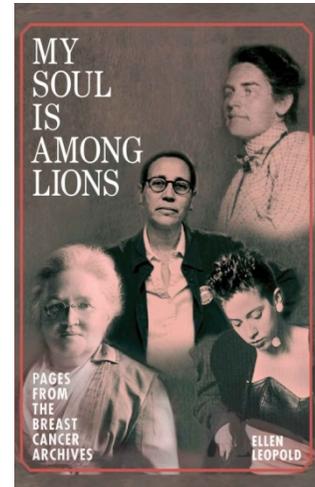
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personal and cultural narratives that show how women, including Leopold herself, have intervened in the course of this disease: some publicly, some privately, some written out of history, some by writing the history themselves, and some, thanks to Leopold's book, now written back into history. This book celebrates "agents of change:" the women who have made a difference.

So of course, Barbara Brenner is among them.

There are a number of things I love about this book, not least of which is how beautifully it's written and how effortlessly it reads. Like a book of short stories, you can pick and chose between the chapters or read them one after the other. The book begins with an introduction that plots a history of women's intervention into the breast cancer epidemic, beginning with Leopold's own involvement with grassroots breast cancer activism at the Women's Community Cancer Project. Over 20 years ago, Leopold co-authored an article about obstacles facing low-income women diagnosed with breast cancer for the leading feminist newspaper *Sojourner*. After the introduction, Leopold then takes a step back to draw from the archives of women writing about breast cancer.



What emerges are a range of formats seized upon by women to talk about their experiences with the disease, many of them not obvious (or available) to the public eye: letters written privately between women because there was no public forum for women to speak out about breast cancer, let alone mention a disease so closely associated with such a highly sexualized body part; this same content then shared among a small community; and, legitimizing years later, the published memoirs and diaries of "celebrities" living with breast cancer. Doctors, researchers, artists, activists, academics all who have played a role, some of them in the margins—albeit the white, educated, middle class margins—but who unequivocally have made a difference in the course of how we understand this disease and by extension, provoke us to ask "how can we do more?"

There were moments early on when I became infuriated that time has not more speedily moved us past much of what faced our predecessors. Leopold writes that in the early 1900s when breast cancer did surface in print "the disease was often traced to 'inappropriate' behavior' on the part of the hapless female victim—too much dancing, exercising, or thinking were often cited" (7). Today, we still see that burden of responsibility put on women to not get breast cancer: eat better, exercise more, breastfeed, buy only organic/pesticide-free/chemical-free personal care products. This absolutely unacceptable message is the same: if you get this disease, it's your responsibility.

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My favorite section is Leopold's reading of obituaries, which for years failed to include the deaths of women. I was shocked to read that the death of breast cancer activist Rose Kushner as late as 1990 marked the first use of the words "breast cancer" in the boldface heading of an obituary (134). When women died of breast cancer, the disease was typically "air-brushed out."

And yet in the face of all of this denial and ignorance, in the face of all the limitations, paternalism and discrimination, Leopold's book reminds us that there are women who for years have been caught up in the struggle with this disease, and who have expressed "an attitude towards the sacrifice of [their] own life that has, bit by bit, moved us forward" (138). I love Leopold's unapologetic work to write these women back into history, for they are women whose lives and work significantly changed or challenged the course of this breast cancer epidemic.

And I appreciated Leopold's candor in naming those who, in her estimation and in mine, have not done enough. Those large, mainstream corporate charities who walk the path of least resistance by mirroring the mainstream cancer establishment's "reluctance to get involved" when it comes to providing real services to low-income women and will pay generously for "everything but surgery, radiation and chemotherapy. . . . and treatment for those who cannot afford it . . . but nothing that could be construed as breaking the American taboo on 'socialized medicine' " (151-2).

Cheers to Ellen Leopold and to the heroines of her book. Cheers to Katherine Coman and Katherine Lee Bates, to Jane Elizabeth Lane-Clayton, Kathy Acker, and Samantha King. And, of course, in my humble opinion, the lion among them all, Barbara Brenner.

## In Memoriam: Charlotte Haley, Creator of the First (Peach) Breast Cancer Awareness Ribbon

We celebrate the life of Charlotte Haley, creator of the first "breast cancer ribbon," who died February 2, 2014 at the age of 91 at her home in Simi Valley, CA. She is survived by her three children Leslie, Nancy and Robert, five grandchildren, two great-grandchildren, and her sister Iris.

BCAction members may recognize Charlotte Haley's story from the documentary film [Pink](#)



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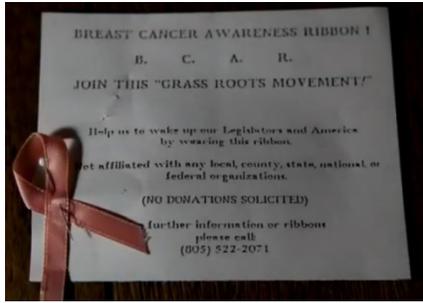
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[Ribbons, Inc.](#) in which she tells the often-overlooked tale of the first breast cancer awareness ribbon, which was not pink in color but peach.

In 1991, Charlotte began hand-making peach breast cancer ribbons in her dining room. To each packet of five ribbons she attached a postcard that read: “The National Cancer Institute’s annual budget is \$1.8 billion, only 5 percent goes for cancer prevention. Help us wake up legislators and America by wearing this ribbon.” Her ribbons were a call to action: a demand for prevention of this disease and greater accountability.



Haley was strictly grassroots, handing the cards out at the local supermarket and writing to prominent women, everyone from former First Ladies to Dear Abby. Her message spread by word of mouth. By the time *Self* magazine called asking if they could use her ribbon in their second annual “Breast Cancer Awareness” issue, Haley had distributed thousands of her peach-colored ribbons for breast cancer prevention.

A savvy marketing executive, Alexandra Penney, then the editor-in chief-of *Self*, and Evelyn Lauder, senior vice president of cosmetics company Estée Lauder saw the potential of a ribbon branded to breast cancer. But Charlotte told *Self* and Estée Lauder that she wouldn’t work with them – they were too corporate and commercial for her. Legal counsel quickly revealed that by changing the color from peach to pink, permission to use Haley’s idea wasn’t necessary. They chose a new color and the now iconic bubble gum pink we see adorning countless products every October was born.

Though Charlotte Haley’s peach ribbon has been eclipsed by its cheerful pink cousin, her grassroots activism and commitment to breast cancer prevention [continue](#) to inspire members of our community. At BCAction, we have always made a point to write Haley back into the history of breast cancer activism. We mourn her death and we applaud her independent grassroots activism and honor her dedication to taking action as a way to address the breast cancer epidemic.

## Welcome to Our New Board Members

*This spring, we welcomed two new members onto our Board of Directors and we are excited to introduce you to them. Our all-volunteer Board of Directors is a remarkable group of people who set the vision for BCAction and lead the organization by determining*

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*organizational policy, assuring the organization's financial security, and representing BCAction's views to the world at large.*

### **Welcome to new Board member Peggy Huston**

Although Peggy Huston has lived in other parts of the U.S., she is from the San Francisco Bay Area and returned here to raise her two, now adult, children. For 13 years, Peggy has worked at the University of California - Berkeley, and over the last four, she's managed an office focused on enabling the financial sustainability of the campus. She met BCAction Executive Director Karuna Jaggar at The Board Match in February 2014, where she was seeking an opportunity to share her talents and experiences to advance a worthwhile mission outside of her daily job at UC Berkeley. She likes to think it was destiny that their paths crossed.



### **Here's what Peggy had to say about joining our all-volunteer Board of Directors:**

In December 2011, I was diagnosed with breast cancer. I'm still learning from that experience. In addition to the emotional shock of being threatened by a cancer, and the physical trauma caused by chemo and radiation, I was also dismayed to learn of the pervasiveness of the disease and the "production line" approach toward treatments. As I began to search for information about the disease, I felt a curtain drawn back to reveal a secret world. I met many people – some of whom I had known for years – who'd fought the same battle without me even knowing. While chemo and radiation has become easier to tolerate than it was 40 years ago, and screening mammograms are now ubiquitous, we don't seem to have made much headway in decreasing the occurrence of the disease. This made me ask, "What are we doing about this?"

I was angry when the medical professionals who were treating me tried to push me out of the decision-making process on how the cancer in *my* body would be treated. Their approach was to recommend patients see a counselor to help with their emotional reaction, don't ask any questions about the prescribed treatments, and trust that the doctors knew what was best. Again, I questioned: "If you know best, why isn't the number of women diagnosed with breast cancer decreasing?"

Breast Cancer Action offers the opportunity to advocate for those who face breast cancer now, and to contribute toward finding a solution that will end this breast cancer epidemic. I

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look forward bringing my experience working in Finance and non-profit management to Breast Cancer Action and to serving as a member on the Board of Directors.

### Welcome to new Board member Shobita Parthasarathy

Shobita Parthasarathy is an associate professor in the Ford School of Public Policy at the University of Michigan, where her research explores politics and policy related to science and technology. She's performed extensive research on the political and policy environment related to breast cancer (particularly



genetic testing and gene patents) in the United States and Europe, which culminated in a book, *Building Genetic Medicine: Breast Cancer, Technology, and the Comparative Politics of Health Care* (MIT Press, 2007). This work influenced the [2013 Supreme Court decision to end human gene patents](#), in which BCAction was a plaintiff.

Shobita is currently working on her second book, which compares civil society activism related to the patent system in the United States and Europe. Civil society activists have challenged how patent systems understand the public interest, and argued that the patent system needs to pay more attention to health, moral, social, distributional, and environmental concerns. Gene patents are a major object of study in this analysis, as are other kinds of "life form" patents.

### Here's what Shobita had to say about joining our all-volunteer Board of Directors:

I first encountered BCAction when I was doing the research for my first book; BCAction played a pivotal role in shaping the early politics of BRCA gene testing! And, I encountered the organization again through our mutual work on the [2013 Supreme Court case](#). In all of these interactions, I have always been impressed by the organization's commitment to achieving health and social justice for all women affected by breast cancer. So, I was thrilled when I was asked to join the Board of Directors!

I'm hoping that my background and expertise can be useful to BCAction in a few ways. My research analyzing civil society activism in technical policy domains may be useful as the organization continues to develop its excellent advocacy work. I look forward to connecting BCAction's work with academics who are doing research related to the social, health, and environmental implications (particularly connected to health and environmental inequalities) of new science and technology related to breast cancer.

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BCAction is fearless and has enormous integrity as an organization. It isn't afraid to take principled positions on controversial issues, and backs these positions with strong evidence and advocacy. BCAction thinks critically about the health, environmental, scientific, medical, social, and political issues affecting breast cancer. Rather than simply accepting the conventional and accepted answers, BCAction develops its advocacy efforts and strategies by thinking in deep and serious ways about what will improve the lives of all women at risk of and living with breast cancer.

I think that breast cancer activism has made enormous strides over the last 25 years. There's widespread social awareness of the disease and prevention and treatment tools, and there's been a dramatic rise in focused research funding and some treatment improvements as well. So, the time is now ripe for the next steps. I'm particularly interested in changing the public conversation so that awareness, and focusing simply on more research and more treatments are no longer seen as enough. We need to convince government and industry to make prevention and treatment tools more widely available, to take quality of life and health justice (including health disparities) seriously as they fund research projects and make drug approval decisions, and to think more critically about the role that social structures play in breast cancer incidence and survival.

*This summer issue of The Source is full a great reads, yet you'll notice that it's slightly shorter than usual. You'll recognize many of our regular features but what you won't see included is the list of donors who have given in honor and/or memory of someone since the last issue of The Source. We will be publishing a list acknowledging all of you in the coming months. In the meantime, please accept our deepest thanks for your ongoing generous support.*

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