



## From the Executive Director: Honoring the Legacy of BCAction's Founders

By Karuna Jaggur, Executive Director

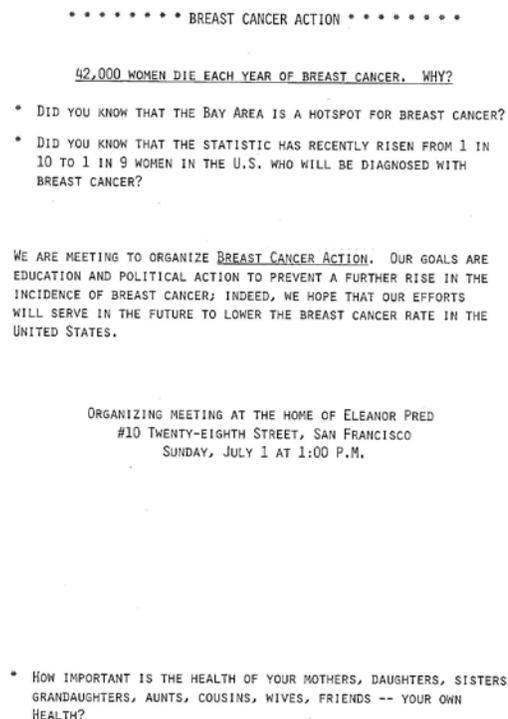
July 1<sup>st</sup> marks 25 years since the very first meeting of Breast Cancer Action's founders.

Since day one, BCAction has been strictly grassroots and run by women living with breast cancer and those who care about them.

Some of BCAction's founders got to know each other at a support retreat for women living with breast cancer. They wanted to find other like-minded activists who shared their anger that more wasn't being done to address the disease they were living with – and dying from – and their urgency to do something about it, both for themselves and for their daughters and granddaughters.

The outreach flier they developed from their first meeting read: *"We are meeting to organize Breast Cancer Action. Our goals are education and political action to prevent a further rise in the incidence of breast cancer; indeed, we hope that our efforts will serve in the future to lower the breast cancer rate in the United States."*

Twenty-five years after that first meeting, we carry on our founders' fearless vision and commitment to education and political action. When 40,000 women will die of breast cancer this year, it's hard to say we're *celebrating* anything. But we are certainly *honoring* 25 years of activism, education, challenging assumptions and telling truth to



*Flier for BCAction's first meeting*

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power.

Of the small group of women who founded BCAction, Belle Shayer is our only living founder. Every time I talk to Belle, she says she can't believe that the grassroots organization she helped found is still here and she is so proud of how strong and effective BCAction is. She also says she can't believe that BCAction's work is still so necessary. She would have hoped that 25 years later, the medical, research and regulatory communities had made more progress on this disease.

We've accomplished a lot together, and we still have a long way to go. Both things are deeply true and we sit with this truth every day here at BCAction.

I hope you can join us October 8<sup>th</sup> in San Francisco, CA for our 25<sup>th</sup> anniversary event -- save the date to honor 25 year of activism with us (you can go to <http://www.bcaction.org/events/25th-anniversary-event/> for more info). I know some of you are planning to travel from out of state for the event – so be sure to also mark Monday, October 12<sup>th</sup> on your calendar, when we'll have a public lecture with a special guest (soon to be announced!)

Thank you to all of you who are part of the BCAction community, whether you've been with us from the very beginning or have just found us recently. Every day I am reminded that BCAction only exists because a small group of people joined together to create change in how breast cancer was perceived and treated. 25 years later, we are carrying on that legacy together.

## 3 Things You Can Do to Help End the Breast Cancer Epidemic

By Alyssa Figueroa, Campaigns Coordinator

We don't have "Action" in our name for nothing.

Since we last talked to you, we've been working on several fronts as the watchdog for the breast cancer movement. Here are several ways you can take action to demand systemic change and help end the breast cancer epidemic. Visit <http://cqrcengage.com/bcaction/> to take action.



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1. **Insist on Strong Chemical Safety Reform:** Each day, we're all exposed to chemicals that increase our risk of breast cancer. That's why we need true reform of our chemical safety laws which currently do not protect our health. An industry-friendly bill is set to make current regulations even worse, further endangering our health and further increasing our risk of breast cancer. This is unacceptable. Tell your Senators to oppose this bill now.
2. **Advocate to Ban Fracking on Public Lands:** More than 700 chemicals are used in the fracking process, and 25% of them are linked to cancer. That's why we're pushing for a fracking ban on public lands. Tell your Representative to co-sponsor the strongest piece of federal legislation against fracking to date.
3. **Support the Lymphedema Treatment Act:** Lymphedema is a common, debilitating side effect of breast cancer treatment. But not all women can afford the care they need. That's why we're joining our friends at the Lymphedema Advocacy Group in supporting the Lymphedema Treatment Act, which would require Medicare to cover lymphedema treatment. Tell your representative to support the Act today.

## Top 10 Articles from the Blog

*By Caitlin Carmody, Communications Officer and Alyssa Figueroa, Campaigns Coordinator*

Here at Breast Cancer Action, we've been working hard to make sure women have access to the evidence-based, patient-centered information they need to help make their healthcare decisions. We've also been advocating behind-the-scenes on important issues like mammography screening guidelines and breast cancer treatment development.

We've rounded up some of the most important information we put out over the last few months so you have it all in one place – from national op-eds to educational webinars to our analysis of new breast cancer studies. You can read the complete articles listed below on our blog at <http://www.bcaction.org/blog>.

If you have any questions, get in touch with us by calling us toll-free at 877-2-STOPBC or by email at [inquiries@bcaction.org](mailto:inquiries@bcaction.org).

### How the TPP Trade Deal Could Increase Risk of Dying of Breast Cancer

Our executive director Karuna Jaggar's latest op-ed in *EcoWatch* explains how the Trans-Pacific Partnership (TPP) is a disastrous deal for both breast cancer patients and breast cancer prevention. Read why we're telling our legislators: "Don't trade away our health!"

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### **Beyond “Awareness”: Metastatic Breast Cancer (Webinar)**

Women don't die of cancer that stays in the breast – they die when the disease spreads to other parts of the body – what's called metastasis. For all the “awareness” of breast cancer these days, important facts about metastatic breast cancer often remain in the shadows. Tune into a recording of our most recent webinar to learn more about metastatic disease and what you can do. <http://www.bcaction.org/resources/webinars/>

### **Stop routine breast cancer screenings. Science has shown they don't save lives**

*The Washington Post* published an op-ed by our executive director Karuna Jaggar about the U.S. Preventive Services Task Force's recently released draft of their new breast cancer screening recommendations. Read why these recommendations don't go far enough in following the evidence about the shortcomings of mammography.

### **New Study Shows Half of Women With Dense Breasts Have Average to Low Cancer Risk.**

Breast density is a hot topic in the news – and state legislatures – these days. What does breast density have to do with breast cancer risk, and what can women do with this information? Read the commentary from our executive director, Karuna Jaggar.

### **Comments to the United State Preventive Services Task Force re: Draft Guidelines for Mammography Screening**

In May we submitted our official comments to the United State Preventive Services Task Force (USPSTF) about their new draft guidelines for mammography screening. Read what we have to say about these always-controversial guidelines.

### **Study Demonstrates Overtreatment Due to Misperceptions About Double Mastectomy**

In recent years, many researchers and health writers have noted that more women are choosing to have their healthy breast removed at the time of a breast cancer diagnosis. A new study shows women may not be receiving unbiased, evidence-based information from their doctors about the risks and benefits of a contralateral prophylactic mastectomy (CPM).

### **Comments to the FDA on Patient-Focused Drug Development for Breast Cancer**

Earlier this month, we submitted our official comments to the Food and Drug Administration (FDA) on patient-focused drug development for breast cancer. The agency that is charged with

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ensuring that drugs and devices are safe and effective should put patient interests – not corporate profits – first.

### **The Trials of Clinical Trials: The Importance of Including Everyone (Webinar)**

All too often, clinical trial participants are overwhelmingly white and male. If not enough women and people of color are included in clinical trials, determining how diverse populations are affected by a new drug or device is impossible. Tune into this recording of our April webinar to learn about the importance and benefits of participant diversity in clinical trials, innovative methods to improve participation, and the advocacy work being done at the FDA.

<http://www.bcaction.org/resources/webinars/>

### **EPA Report on Fracking and Drinking Water Only Skims the Surface**

Earlier this month, the Environmental Protection Agency (EPA) released a long-awaited report about the impacts of fracking on drinking water. Our policy intern Aliza Kazmi digs into what the EPA's report can – and can't – tell us.

### **New Study Explores Impact of "Cavity Shave Margins" During Lumpectomy**

A majority of women who are diagnosed with breast cancer—up to 90% by some estimates—are candidates for lumpectomy followed by radiation (which reduces the risk of recurrence in the same breast.). A new study explored the impact of removing more tissue all the way around the tumor site during the initial surgery, a practice called cavity shave margins (CSM).

## **Meet Our New Community Leader for Change**

*Our Community Leaders for Change program continues to grow, and we're honored to introduce our newest member, Valerie Deering. For more information about the Community Leaders for Change program or to become a Community Leader, please contact Alyssa Figueroa at 415-243-9301 x11 or [afigueroa@bcaction.org](mailto:afigueroa@bcaction.org). You can also learn more about the program by visiting <http://www.bcaction.org/resources/speakers-bureau/>.*

I was diagnosed with end stage breast cancer in 2010 and I'm still here. I am happier and healthier than I have ever been. I have spent the last 15 years in the mental health field, educating people and assisting them with their rehabilitation journeys. I have recently evolved my focus to include trauma rehabilitation, specifically healing the entire system, both mental and physical. In 2014, I received my Reiki Master training. I love to help people heal.

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I spent many years running 5ks in the name of breast cancer prevention until I discovered the documentary Pink Ribbons, Inc. and realized my time could and would be better spent. That led me to Breast Cancer Action in 2013. My first activity was a screening of that powerful movie, and it's now an annual event in my community. I look forward to building community in my area with even more of these types of events.

I became a Community Leader for Change with Breast Cancer Action because education around the disease is sorely needed. My own experience being treated for breast cancer raised my awareness of how we handle the disease and sensitized me to who is getting it. I was 39 years old at the time of my diagnosis and felt that I was "too young." I have since met many women who are diagnosed much younger than I was. I also became sensitized to the whispering that we, as a society, do about the realities of breast cancer and actually experienced it in my own "tribe." This increases our anxiety about it. We need to put the power back in our hands and we can do that by educating ourselves. I strongly believe in the mission of Breast Cancer Action and believe that together we can make a difference!



Valerie Deering

## Member Perspective: 'Stop Trying to Make Cancer Pretty'

*The following is a Q&A that our Campaigns Coordinator, Alyssa Figueroa, did with BCAction member Sandra Allegrini regarding an article recently published on The Huffington Post with the headline "Making Cancer Pretty." Sandra has been a member of Breast Cancer Action since 1993 after her first breast cancer diagnosis.*

**Alyssa Figueroa (AF):** What was your reaction to the article, "Making Cancer Pretty"?

**Sandra Allegrini (SA):** Initially the title, 'Making Cancer Pretty,' was just an affront because it reinforces the idea that if we put some makeup on [cancer], we can cover up all the nasty stuff behind cancer. In an industry that continues to put things that are carcinogenic, like parabens and phthalates, which are endocrine-disruptors, in their products, and then says that they

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support breast cancer awareness—well, I'm very aware of breast cancer. I don't need awareness, I need somebody to fix it.

We're getting there slowly, but I just think when you have articles like that, it gives the wrong impression. When I was diagnosed, I went to events like this—I don't know if it was "Look Good Feel Better," but it was, 'Come in and we'll give you some makeup and we'll show you how to do your makeup while you're going through chemo.' But it's old makeup. It's makeup that has parabens or fragrances in it. And we just keep glossing over [these facts]. It makes those that provide the makeup feel good, but they are promoting the problem.

Beauty products, the author wrote in this article, 'could reverse the tolls of chemotherapy.' Have you ever gone through chemotherapy? You can't put makeup on and reverse what it's doing to you. And those tolls of chemotherapy are life-lasting for many women. It doesn't go away by putting a little makeup on.

**AF: How does your reaction relate to your experience with breast cancer? You were diagnosed with breast cancer in 1993?**

**SA:** Yes, twice, in 1993 and in 2009. My reaction to this article was based on my experience with breast cancer. I don't think that you can tell me that the beauty industry is interested in finding a cure for breast cancer. I don't see it on any level. I don't see it with Revlon. I don't see it with the walks or sticking a pink ribbon on my lapel in October. In fact, I won't wear pink in October. And I like pink! But I'm not going to wear it in October. So it's from that perspective. [No one is] getting it.



**AF: Why do you believe the cosmetic industry is not addressing the realities of breast cancer?**

**SA:** I don't know that an industry like that can address it. I think it's too serious a thing. It's a business, right? They're in the business of selling makeup. Those two things are contradictory. 'I'm in business so I want to sell this product, so in order to sell this product, I have to make you want it. So I give it to you in many ways. I give it for free to some people. I give you samples.' If you try something or you touch it, you're more likely to purchase it, right? They do that at makeup counters all the time. 'So just by giving you my makeup I'm going to make you

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purchase it later. I have a greater probability of making a sale later than I do now by giving it to you for free.' But your product may be causing breast cancer because of your ingredients.

**AF:** Earlier you said you won't wear pink in October. Can you say more about why?

**SA:** I'm not going to wear a pink ribbon. Breast cancer is not a pretty disease. It's a horrible disease, as are all cancers. You can say that for all of them. And it just feels like we gloss over it all. If I give you some makeup or a pink ribbon to wear, you feel good because you think you're doing something good, but you're really doing nothing and we're doing more for the industry than for people who have breast cancer. It just feels wrong to participate in that.

## Special Thanks: Summer 2015

We could not do this work without the support of so many members and volunteers. A huge thank you to:

- **C.J. (Dian) Corneliussen-James**, Co-Founder and Vice President and Director of Advocacy for METAvivor and **Lori Marx-Rubiner**, blogger at [www.regrounding.com](http://www.regrounding.com), former Board President of METAvivor and BCAction Community Leader for being wonderful guest presenters on our "Beyond "Awareness": Metastatic Breast Cancer" webinar in June.
- **Galen Joseph**, Associate Professor in the Department of Anthropology, History and Social Medicine and Helen Diller Family Comprehensive Cancer Center at the University of California, San Francisco and **Cindy Pearson**, Executive Director of the National Women's Health Network for being wonderful guest presenters on our "The Trials of Clinical Trials: The Importance of Including Everyone" webinar in May.
- Big thanks to **Rob Weissman & Public Citizen** for providing tickets to Stand Up for Main Street at the SF Jazz Center.
- **Alan Kleinschmidt and the SF Choral Society** for providing tickets to their extraordinary concerts.
- **Elizabeth Harman** for her invaluable assistance during our year-end fundraising.



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- **Sara Brandon** for her ongoing and dependable administrative support.
- **Kathleen Toland** for helping to expand BCAction's network, fundraise and spread the word to Salesforce employees and beyond!
- The **Board and former Board** for their tireless volunteer work and their unparalleled commitment to and trust in our work, including initiating a generous matched giving challenge!
- **Ken Fischer** for his passionate commitment to Breast Cancer Action for more than 20 years and the generous gift of his time and talent to support our work and 25th anniversary.
- **Galen Joseph, PhD, Julie Harris-Wai, PhD, MPH and Julia Lyandres** for participating in an informative and productive panel on treatment development, clinical trials, and patient-centered research at our annual Board/Staff retreat.
- All of our members who started **Don't Pink for Me fundraising pages**, shared their stories, and helped raise money to fund our work.
- And last but not least, the **wonderful Salesforce team** who helped us send out a big mailing this spring.

## Donations in Honor and Memory: Summer 2015

*Every day, Breast Cancer Action receives gifts honoring those who are living with or affected by breast cancer. We also receive contributions to honor the passionate advocates, volunteers, medical professionals and leaders of the breast cancer movement.*

*Many donations also memorialize those who have died of this disease. Each gift made in honor and memory will be used wisely by Breast Cancer Action to end the breast cancer epidemic.*

### *Donations Made in Honor*

*BCAction gratefully acknowledges donations made in honor of the following individuals between March 25, 2015 – May 25, 2015.*

Jeannie Abels  
from Beth Abels

Abigail and Elissa Arons  
from Joy Riskin

Melanie Adrian  
from Kristin Bright

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Elissa Arons  
from Yvette Drury Dubinsky  
from Judith Chasin  
from Lynne Golomb

Linda Azer  
from Nicholas Azer

Lois Beach  
from David Fairchild

Joyce Bichler  
from Marcia and Alan Kimbarow  
from Vickie Dandridge  
from Rosey Rudnick

Sara Brandon  
from Rochelle and Marvin Brandon

Sean Camp  
from Armand Ruby

Gary Collin's retirement  
from Robert Sehr  
from Anne M. Ablaza  
from Joseph Moussa  
from Gargi Nagwekar  
from Michael D. Sullivan

Piera Fico  
from Dina Fico

Janet Frost  
from Gail and Barry Kaufman

Margaret Fuller  
from Laurie Fuller

Marlyn Geisert  
from Leslie Doyle

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Janet Lee  
from Stephanie Foster

JoAnn Loulan  
from Tracy Sherman  
from Norman Schwartz  
from Pamela Dorrell

JoAnn Madigan  
from Paul Bellina

My sister Mary  
from Donna Harris

Rachel Morello-Frosch's birthday  
from Peggy and Gary Dorfman  
from Ruth and Alexander Weil

Julie Morgan  
from Christopher Gantz

Anna Nowak  
from Kristine Lange

Cindy Pacheco  
from Kimron Thomas

Dorothy Polash  
from Frank Woo

Faith Raider  
from Barbara Raider

Gail Reed  
from Jessica Ross

Rebecca Rowe  
from David Fairchild

Ruby Seidl  
from Karla Ebrahimi

Adrienne Torf's birthday  
from Joanne K. Stratton-Mamber  
from Barbara Goldberg

Barbara Ulrich  
from Ellen Melamed

Elaine Wise  
from Erin Wise

Nicole  
from Shannon Shafer

The Women of Smith 1973  
from Robbie Lipsman

Too many friends and relatives, and myself  
from Jessea Greenman

Valerie  
from Sarah Andropoulos

### *Donations Made in Memory*

*BCAction gratefully acknowledges donations made in memory of the following individuals between March 25, 2015 – May 25, 2015.*

Joyce Ambrosini  
from Margaret G. Langston

Rita Arditti  
from Barbara Rubin

Barbara Brenner  
from Penelope Cooper and Rena  
Rosenwasser  
from Nancy and Donald Grail  
from Helen Love  
from Patricia A. Murphy  
from Laurie J. Woodard  
from Susan Liroff  
from Bella August

Frances Cameron Montgomery  
from Elisabeth Rosen

Christina Cryan  
from Thao Nguyen

Barbara Deitcher  
from Mari Deitcher

Mel Delapine  
from Marion Thurnauer

Christine Eisenhardt Gardner  
from Kirsten Gardner

Richard Esposito  
from Sylvia Baker

Sue Fine  
from Joyce Bichler

Billie Gardner Loulan  
from Tracy Sherman

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Jeanette Goldfish  
from Lauren Goldfish

Katherine "Tinka" Gordon  
from Franklin Lowe  
from Allen Toy  
from Peter Mattson  
from Melinda Winter  
from Darin Lounds

Suzanne Hall Vogel  
from Eve Vogel

Jean Hardisty  
from Ellen Leopold

Laurel Hedley  
from Mary Hedley and Stephen P. Morrell

Cecile Howard  
from Mary Patricia Ryan  
from Alexis Danzig  
from Gary Howard  
from Barbara Huggins  
from Candie Wilderman  
from F. David Constance  
from Carole Sullivan  
from Richard Synnott  
from Margaret Gilmartin  
from Lauren Goldfish

Karen Hunter  
from Maurin McCutchen

Mary Margaret Koch  
from Claudia Mazzetti

Ellen Lew  
from Anonymous

Robert Leipsic  
from Julie Miller

Felicia Louie  
from Anonymous

Roberta Lovenwirth  
from Joan Donsky

My mother, Ellen Rice Lowery  
from Margaret Lowery Walsh

Jane MacDuffie  
from Monica Beardsley

Liz Marek  
from Anne Thorkelson

Cheryl McMillan  
from Donna Zacchero

Forestine Monsen  
from Erin Wise

Mary Utne O'Brien  
from Ingrid O'Brien

Ellen Palmer  
from Marianne Sargent

My mother, Fay Parrish  
from Donna Mysior

Teresa Peters  
from Sean O'Connor

Bill Potter's mother  
from Julie Cowan and Neil Good

Joseph Priven  
from Carole Priven

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Mignon Richmond  
from Simone Richmond

Kate Romani  
from Nancy Dornenburg

Sarah Routte  
from Lauren Goldfish

Beatrice Schorr  
from Ethlynn Schorr

Kyra Shafran Griffitts  
from Nina Shafran

Mirian Shapiro  
from Dianne and Nelson Shapiro

Lucy Sherak  
from Ken Fischer

Catherine Wallace Joseph  
from A. Lee Miller

Betsy Wood  
from Frances Wood

Barbara Woolf  
from Dotti Webb

My aunt, Dora  
from Stephanie Schus

Too many friends and relatives  
from Jessea Greenman

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