



From the Executive Director: Planning for the Next Five Years & Beyond

By Karuna Jaggar, Executive Director

Let's face it: Breast Cancer Action does controversial work. Our members are outspoken and opinionated and you aren't afraid to tell us what you think — including when you think we're on the wrong track.

In January, we asked you to tell us what you think about our current work and priorities as we plan for the next five years at BCAction. We were prepared to be challenged and questioned by you. We were prepared for an earful!

And we were overwhelmed (in a good way) by your responses! More than 1,330 people participated in our paper and online survey. And dozens more of you joined us for confidential interviews and focus groups. What we heard from you was so insightful and energizing.

Overwhelmingly, you told us that Breast Cancer Action does important work, that you trust what you hear from us, and that we fill a unique roll that is different from most other breast cancer organizations. You described us as a knowledgeable, fearless, truth-telling organization that provides unbiased, evidence-based information and stands up for women living with breast cancer. You said Breast Cancer Action educates you on important topics. And you told us that you want to hear more about primary prevention of breast cancer and environmental links, treatment issues, and our role as a watchdog.

In addition to our survey, as part of the strategic planning process we asked two U.C. Berkeley Board Fellows to conduct an independent landscape analysis of the breast cancer field. Their findings clearly highlighted our unique role as a watchdog and illuminated the uniqueness of our role as activists and our conflict of interest policy. Specifically, we continue to stand out in our field by not taking donations from any entity that would present a conflict of interest for us in our work (including pharmaceutical, chemical, and health insurance companies).

Through our strategic planning, we've affirmed our commitment to social justice as we work to create a healthier and more just world for all women. As an organization that views breast cancer as a public health crisis and a social justice issue, we recognize that different communities experience the breast cancer epidemic in different ways. As long as some communities bear a disproportionate burden of breast cancer, we will work to bring health



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justice for all women at risk of and living with breast cancer. We know that we can't do this work alone and we recognize the connections and intersections between the issues we work on as BCAction and the important work being done by our partners and allies.

We will continue to be a leader in our work to:

- Put patients before profit: we will hold the powerful accountable to our public health
- Democratize the science
- Draw connections between issues
- Build grassroots, activist leadership
- Highlight women's diverse lived experiences
- Demand people-centered/public health policies and regulations
- Lead corporate campaigns
- Demand evidence-based medicine

And we will always look to systemic solutions to stop cancer before it starts and to meet the needs of women living with breast cancer.

In terms of what lies immediately ahead, spring is event season for us (and many organizations) and I hope to see you at one of our events across the country. By the time this issue is published, I will have been celebrating with many of you at our 10th Anniversary Billie Gardner Loulan Memorial event in the San Francisco Bay Area and at "Seeing Red: The Truth About Pink Ribbons," a BCAction community event in Boston. I look forward to meeting up with many of our San Francisco Bay Area friends at "Acting Out: For the Health Of It" on May 1st or one of our other community events.

I'll share more about our strategic planning process over the coming months as we look ahead to the next five years and beyond. Thank you for being part of our community and strengthening this movement to shift the balance of power from corporate profit to public health.

Mammography for Black Women: Why I Won't Be Silent Anymore

By Tracy A. Weitz, PhD, MPA, Chair of Breast Cancer Action's Board of Directors

Back in February, a new study, this one published in the *BMJ*, again questioned the value of screening mammography in the general population. This is a "gold standard" study with a large randomized sample followed over a significant time period: "Twenty five year follow-up for breast cancer incidence and



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mortality of the Canadian National Breast Screening Study: randomised screening trial.”

This study from Canada found no reduction in mortality among women diagnosed with breast cancer discovered with or without mammography. Breast Cancer Action immediately raised our longstanding concerns about the lack of clear benefit to screening (as opposed to diagnostic) use of mammography in the general population. In responding to the study, the question was rightfully raised about why a study of almost all white women could be extrapolated to say anything about the value of mammography in the African American population.

Had I made that easy slip of assuming that studies about white women can be universalized to all women? Had I spoken for women that I do not represent, or women whose experiences I do not share? Should I temper my comments to say I think this research tells us why white women should think more critically before blindly following their doctors' recommendations that they get regular mammograms? As a white woman, should I stay silent and sit out this fight?

As I contemplated these options, I felt the tears well up in my eyes. I remember all too well what silence bought me before. My silence helped cost me my mom and it cost my mom not only her life but her dream. Diane Olds, my beloved mom, was diagnosed with breast cancer in her early 50's following a routine screening mammogram. At that time, we didn't know much about Ductal Carcinoma in Situ (DCIS) and the recommended treatment was surgery, followed by radiation and chemotherapy, and then hormonal therapy in the form of Tamoxifen. Despite being a women's health activist, I didn't know much about breast cancer treatment and we dutifully complied with this recommended regime.

As the years progressed, I studied the breast cancer issue, followed the science, and engaged with leading scholars in the field. I began to question whether the mammogram that led to my mom's diagnosis was necessary and whether the cancer they found really needed to be treated. But I stayed silent. "What good would come from my raising this question?" I asked myself. By this point, my mom had decided not to complete her doctoral degree. She had found it too hard to balance treatment, teaching (she was an elementary school teacher) and data collection for her dissertation. Like many women her age, my mother had already delayed pursuing additional education until after her children were out of the house. She had always wanted to be Dr. Olds, but now, managing her health seemed more important. Furthermore my mom was a proud "breast cancer survivor." She did the walks, the runs, and her house was filled with pink ribbon paraphernalia. She believed the mammogram saved her life and was grateful.

In 2005, ten days after she started complaining of shortness of breath, I lost my mom to an aggressive uterine cancer caused by her breast cancer treatment. By then, the world knew that ten years of Tamoxifen put women at risk of a horrible side effect – uterine cancers.

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This is why I care so deeply about the over-diagnosis caused by routine screening mammography. While the cause of my mom's death was a very rare side effect, her death is emblematic of a larger set of harms that come when we turn healthy people into cancer patients.

The mantra "early detection saves lives" makes intuitive sense. Find breast cancer before it grows and the outcomes have to be better, right? Wrong. The science just doesn't support this narrative anymore. This latest Canadian study is one more study questioning the assumption that mammography as a screening tool reduces mortality in the general population. Additional analysis, done both in the U.S. and in Europe, finds that most of the benefit historically attributed to screening mammography is actually the result of improvements in treatments.

But aren't all of these studies of white women and isn't my mother's story a story of a white woman, and of white women's breast cancer? Yes, yes, and yes. But that doesn't mean that black women should think the story is different for them.

Yes, black women aren't included in most of the studies that show harm from mammography. But ironically, adequate numbers of black women were not present in the studies that showed mammography might be beneficial either. Rather this latter idea was just accepted on faith with the hope that perhaps this tool could stem the higher mortality rate from breast cancer among black women.

So here is my outrage. Black women, like white women, like all women, got sold a bill of goods. They were told that screening mammography would save their lives. Breast cancer in black women appears earlier and is more aggressive. So it makes sense that we would think mammograms would be more beneficial in this population, even if they are not helpful in the larger population. But the evidence is just not there. At the population level, the screening rates for black women have risen dramatically in the last decade. But the mortality rate from breast cancer has not reduced correspondently. And mammography is very bad at detecting cancers in premenopausal women, so more application in younger women doesn't help either.

I am outraged that even after this many years of knowing the limitations of mammography and the reality of higher mortality rates of breast cancer in black women we still don't have a better screening test and we haven't figured out how to treat the bad breast cancer – the one that appears earlier and presents more aggressively, the one that black women get more often.

So why do some hold onto mammography as critical to black women's health with such passion? The answer is really two-fold and has little to do with breast cancer and a lot to do with structural racism. Black women have the worst health outcomes on almost all health indicators. The average life expectancy for a black woman is five years less than for a white woman. And mammography has been the doorway into healthcare for many black women, especially for women in their 40s and 50s who have higher rates of being uninsured than their

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younger counterparts. The campaign to get black women mammograms brought healthcare resources to communities long ignored by the public health sector. Free mammograms were accompanied by visits to the doctor and blood pressure checks—perhaps an even more critical healthcare intervention for this group for whom heart disease and stroke are major causes of disability. And funds were poured into communities to support community health educators who taught women not only about breast health but about nutrition and exercise, information that contributes to health improvements of all kinds.

So I understand that recommending fewer mammograms is not a neutral issue and that overall health status is at risk when mammograms are under attack. But I don't think the solution is to continue to push mammograms for black women. We need universal access to quality primary care; we need financial support for community health workers; we need to acknowledge that structural racism gets under the skin and contributes to poor health outcomes. However, these goals just shouldn't be part of a mammography agenda.

And I won't stay silent about mammography in black women any longer.

There are many amazing black women in my life who serve as my friends and mentors on all matters in life. I will look to them to tell me if I am making the mistake of speaking on their behalf, rather than what I think I'm doing today, which is speaking on behalf of good science for all women. However, in this case, if I remain silent I would just be exercising a privilege of a different kind.

Breast Cancer and the Psychosocial Healing and Well-being of the Whole Person

By Zoë Christopher, Information and Resources Liaison

As BCAction's Resource Liaison, I handle about 500 calls, emails and inquiries every year. Many are from women making difficult decisions after receiving a breast cancer diagnosis – a diagnosis that carries serious social, psychological, and physical implications. I listen to their stories, often heart-wrenching and challenging, talk them through the pathology reports and diagnostic jargon, and help get the information and resources they need to make well-informed decisions about their health.



Every year, Breast Cancer Action attends the San Antonio Breast Cancer Symposium (SABCS), the largest breast cancer conference in the world, where new research is unveiled and discussed. Over the years, I've been reluctant to attend. Why? I was concerned that the industry's emphasis on both pharmaceutical-funded science and what I perceive as an emphasis on profits over people would further inflame my frustrations with the field, what we frequently refer to as "the cancer industry." But in December of 2013, I bit the bullet and,

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along with our executive director Karuna Jaggar, spent five days in San Antonio. The experience provided me some encouragement as well as a sense of urgency.

I've been part of the breast cancer world for seven years and was reminded that not too long ago, before Herceptin, HER2 positive breast cancer was virtually untreatable. Over the last 20 years, there have been major breakthroughs and progress in diagnosis and treatment resulting in better survival rates, but not much attention has been paid to the psychosocial impact of diagnosis and treatment on patients.

All too often, the psychosocial impacts of breast cancer remain the hidden and personal experiences of the women I am in contact with every day. People may call for information that will help them make decisions, but the personal impact of their diagnosis and treatment, the emotional and psychological weight of these decisions, isn't always obvious to me. And I am sure it remains hidden and/or unaddressed by their doctors. Often, when I hang up the phone, I wonder, when we're disconnected, "How is she right now?" When the woman I was speaking to hangs up and is alone again with the palpable reality of her diagnosis, when she isn't trying to hold it together in order to talk to me, how is she then?

Dr. Lesley Fallowfield, professor of Psycho-oncology at Brighton & Sussex Medical School, University of Sussex in the U.K. and a presenter at SABCS 2013, calls for better allocation of resources devoted to psychosocial support related to survivorship. Given the progress in diagnosing and treating the disease, she now considers breast cancer to be an emotional emergency, not the medical emergency it once was.

In San Antonio, every morning I sat through a marathon of 15-minute presentations on various clinical trials, wading through the dense science. I spent my afternoons at the BCAction table, surrounded by the booths of pharmaceutical behemoths like Genentech and Eli Lilly. I loved this part of my SABCS experience because I got to meet and speak with many breast cancer patients, members of BCAction, and patient advocates, all passionate about ending this epidemic, developing more effective and less toxic treatments, and preventing this disease in the first place. At one point, after my exuberant explanation of all our good work, the researcher I was talking to smiled broadly. "I love you guys," she whispered. "How did you ever get in here?" I understood exactly what she meant: at this huge, industry-dominated conference, BCAction is something of "the thorn in the side" of the breast cancer industry.

With session titles like "Final analysis of a phase II 3-arm randomized trial of neoadjuvant trastuzumab or lapatinib or the combination of trastuzumab and lapatinib, followed by six cycles of docetaxel and carboplatin with trastuzumab and/or lapatinib in patients with HER2+ breast cancer," it's easy for me to feel that patients, women that BCAction serves and advocates for, are lost in the science. Yes – today there are more clinical nurse specialists, counselors, and psycho-oncologists. There are more psychotherapists who specialize in the unique needs of breast cancer patients, and we're slowly improving the psychosocial safety net for patients. Dr. Susan Love refers to the current way we tackle breast cancer in this country as "slash, burn and poison." I'm convinced that the consequences of this approach are

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emotional and psychological, just as much as they are physical. We mustn't allow the traumatic impact associated with a breast cancer diagnosis to be minimized or lost in cheerful pink ribbon campaigns. Only if we hear and honor the very real consequences of toxic cancer treatments will we have any hope of creating better ones.

Anyone who has personally experienced breast cancer or knows someone who has experienced this disease is fully aware that a woman's quality of life is deeply impacted by treatment. This often includes a prolonged period of being unable to work, or an inability to return to work following the completion of her treatment. The toll of the combination of financial, physical, emotional and psychological crises is often depression, with resulting fatigue and overwhelming anxiety, which if not addressed and managed, frequently results in poor adherence to treatment or maintenance protocols. Often a woman's entire social network is affected as friends pull away, coworkers disappear, and family members wrestle with a sense of helplessness. She may become withdrawn and anti-social; she may struggle against a sense of dependency or burden; and issues around sexuality are common. None of this is conducive to healing, no matter what her doctors say about how her physical body is responding.

A breast cancer diagnosis can produce anxiety and symptoms of acute adjustment disorders, but the support needs of breast cancer patients can be satisfied through a diverse range of techniques. The latest research makes clear the benefits of non-pharmaceutical interventions. Yoga, massage, visualization techniques, art and music therapies, cognitive behavioral therapy, and mindfulness-based stress reduction improve both emotional states and endocrine-related symptoms, and aerobic exercise reduces fatigue. These were once relegated to alternative or "fringe" modalities, but data now points to the benefits of including them in an integrative treatment protocol.

For some women, a breast cancer diagnosis is no longer the death sentence it once was – women are living longer. At SABCs I found some deeply passionate and committed doctors who presented promising data on treatment for triple negative breast cancer; on the use of bisphosphonates to reduce the risk of metastases in post-menopausal women; and on ways of preventing over-treatment. But I also heard their frustrations at being committed to important work while struggling in a broken healthcare system. This system has also failed to recognize a patient as a whole person whose healing needs are taking place on every level that is impacted by this disease, not just the site of the tumor.

Dr. Fallowfield envisions a future in which a patient enters a clinic, has her tests done, and then completes a quality-of-life survey and symptom checklist. Such information would enable her physician to prescribe and refer her to the supportive services that may actually promote an integrated and complete healing. Such a patient-centered treatment plan will address not only the disease of breast cancer, but the psychosocial healing and well-being of the whole person. I for one am excited to see such a much-needed practice become a reality.

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I feel a sense of renewed urgency after attending SABCS that comes from knowing more about the private side of this disease, and wanting patients to have every opportunity to live as fully as possible with minimal permanent impact from treatment. It's extremely helpful to me to know there are some really good people out there, doing really good work with this end also in mind.

Report-Back from San Antonio Breast Cancer Symposium 2013

By Karuna Jaggar, Executive Director

Report-Back on Aromatase Inhibitors

"The change from brand-name to generic aromatase inhibitors and hormone therapy adherence for early stage breast cancer."

This study showed that 45% of breast cancer patients report that high drug costs often result in some form of "non-adherence," meaning that patients are not taking prescribed treatments. Women who don't take their prescribed treatments have lower survival rates. Not surprisingly, wealthier women (over \$100,000) are more likely to be able to afford, and therefore take, their drugs than poorer women (less than \$40K/yr). When the presenter compared the price of a one-month supply of everolimus (\$9,416) vs. a one-month supply of anastrozole (\$110), there were gasps across the large conference hall. This presentation underscored that patients must come before pharmaceutical industry profits.

"Randomized trial of exercise vs. usual care on aromatase inhibitor-associated arthralgias in women with breast cancer: The hormones and physical exercise (HOPE) study."

This study explored exercise as a remedy for the very common side effects of aromatase inhibitors (AIs). The goal is that if exercise controls side effects, more women will take the treatments, and see improved outcomes. After one year of getting recommended levels of exercise, women taking aromatase inhibitors reported a 30% decrease in joint pain. (Recommended exercise = 2x weekly strength training and 2.5 hrs moderate intensity aerobic activity.) One limit of the study is that we don't know if the benefits are due to aerobic exercise, resistance training, or the combined effect. A number of women chiming in with personal experience said that doing even light exercise like walking helps ease joint pain from taking AIs. How can we make sure all women, in all communities, are able to get the recommended levels of exercise? Social inequities lead to health disparities and we need to support findings on the benefits of exercise with systemic public health solutions.

"Anastrozole for prevention of breast cancer in high-risk postmenopausal women (IBIS-II): An international, double-blind, randomized placebo-controlled trial."

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Researchers reported that taking the breast cancer drug anastrozole (sold as Arimidex) for five years reduced the chances of post-menopausal women at high risk of breast cancer developing the disease by 53% compared with women who took a placebo. This is the report from the IBIS 2 trial that included post-menopausal women who were at increased risk of breast cancer because of family history, DCIS or breast density. Median follow-up was five years. In the placebo arm of the trial, there was a 5.6% incidence of breast cancer (including DCIS) which was reduced by over 50% to 2.8% in the anastrozole arm of the trial.

Although this is a significant finding about anastrozole, the media headlines coming out about this research may overstate the actual significance (for example, the Chicago Tribune ran this story under the headline "Arimidex halves breast cancer risk, study finds"). For one thing, the actual numbers of women being followed are significant but still small. In addition, the absolute risk difference between placebo group and the anastrozole group was only a 2.8% difference, with no difference in mortality rates between the two groups. So we are really talking about risk reduction, not prevention. This is significant reduction in breast cancer risk, but we must be clear to women that it lowers risk by a few percentage points in what is already a low risk; for any one individual, it cannot be said it would prevent you from getting breast cancer.

Another point to note is that the researchers compared anastrozole only to a placebo group, not to a control group of women taking other aromatase inhibitors (AIs). This is concerning because the authors believe anastrozole should be the drug of choice. If this drug is going to be promoted as a replacement for other AIs, we want to know how anastrozole performs not just compared to a placebo but also as compared to the other two AIs that are currently the risk reduction drugs of choice. In other words, is this a better drug than what's already in use, or just a newer (perhaps more expensive) drug?

Last, but certainly not least, the authors of this study seemed to downplay the drug's side effects, focusing on the fact that women need to be educated about side effects as opposed to normal aches and pains of aging. This may make sense except for the fact that other studies (in fact, in the presentation immediately following this one) have shown that in the first year of use, up to 20-30% of women stop taking the drug because of the side effects, most commonly because of muscular and skeletal pain as well as depression, insomnia, fatigue, and cognitive issues.

The authors rightly acknowledge long term follow-up is needed. We would also like to see direct comparisons of anastrozole to other AIs so high-risk women know exactly what their choices are if they consider taking any AI.

Some Notes on "Basic Science"

I've taken to avoiding the sessions about so-called basic science, which is typically only comprehensible to the folks with expertise in that field—even other researchers and doctors

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struggle to follow. But there were two areas in basic science that were widely discussed at SABCS 2013. Here's a quick summary.

Thirty years after widespread medical interest in immunotherapy, we still have not harnessed its potential but there were three papers on the topic at SABCS 2013. Lymphocytes are white blood cells that are part of the immune system. Research has shown that the more of these cells from the immune system (lymphocytes) are found in a tumor, the better the prognosis. A patient's immune system appears to play an important role in chemo, targeted therapies, etc. although we do not yet know how to support the immune system and what interventions can increase the number of tumor-infiltrating lymphocytes.

Stem cells are cells that are able to self-renew and can create two equal cells. Researchers have found there are two types of stem cells in breast cancer: luminal and basal. Although just 1 in 1,000 cells in a tumor are stem cells, they are vitally important because stem cells are resistant to therapy and can regrow the entire tumor months, years, decades later. There has been suggestion from research in animals that a better indicator of prognosis than tumor progression is markers in the form of proteins that are expressed on these stem cells. Researchers' interest in targeting stem cells in the future is reinforced by the finding that some stem cells over-express HER2, even in tumors that are not HER2+. The researcher presenting this information noted that a control group that didn't have HER2 amplification also got significant benefit from that therapy and this may be an area of future investigation.

Updates on HER2+ Drug Trials

HER2+ breast cancers account for 20-30% of breast cancer diagnoses. There were some updates on HER2+ drug trials presented in years past, and researchers now have more mature data.

The first trial reported on, Neo-ALTTO, looks at whether adding Lapatinib to Trastuzumab (Herceptin) is beneficial to patients. Lapatinib is another HER2 antagonist. The study design asks whether the incremental gain in pathological complete response (pCR) observed with dual HER2 blockade translates into improved event-free survival (EFS) and overall survival (OS).

pCR means that the tumor has completely disappeared from the breast and lymph nodes. pCR is used as a surrogate endpoint after an Food and Drug Administration (FDA) meta-analysis showed that pCR is linked to longer overall survival. We have to be very careful with this approach which has not been shown to be true for ER+ cancers.

In the Neo-ALTTO study, presented by Dr. Martine Piccart-Gebhart, patients who achieved pCR had significantly better event-free survival and overall survival, irrespective of the treatment arm they were in. At approximately a four-year median follow-up, dual HER2 blockade appears to provide better pCR, EFS, and OS benefit for patients with HER2+ hormone-tumors. Overall survival was improved for patients experiencing pCR, with a 60% reduction in mortality. HR negative tumors are the greatest responders, but researchers didn't

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see the same impact on ER+ with statistical significance. These are slower-growing tumors that can have late recurrences, so it's possible they've not had enough time to see whether there is a similar benefit.

It is always important to balance potential benefit with safety analysis and quality of life for patients. The most commonly experienced side effects women include diarrhea, liver enzymes, and rash. One in four patients taking lapatinib in the trial experienced severe diarrhea and patients on the trastuzumab experienced significantly fewer side effects compared with those in the combination and Lapatinib arms. Indeed, only two thirds of patients were able to complete treatment of lapatinib in both phases. In contrast, 90% of patients on the trastuzumab completed their treatment in the neoadjuvant phase, with 80% completing the treatment in the adjuvant phase.

The second Her2+ study, TRIO-US B07, presented by Dr. Sarah Hurvitz, shared the final analysis of a Phase II three-arm randomized trial. This is only a Phase II trial (drugs don't come to market until Phase III), so I won't discuss this study other than to say I am pleased that there will be an analysis of patients who did not get pCR.

The third trial, the BETH trial, presented by Dr. Dennis Slamon, was a negative trial that failed to show any benefit to patients from adding Avastin (bevestuzumab) after surgery for HER2+ tumors. The study compared invasive disease-free survival in patients treated with chemo and Herceptin versus chemo and Herceptin with the addition of bevacizumab (Avastin). After 38 months, 92% of patients had disease-free survival for both trial arms—somewhat of a surprise that it was so high. The main difference was in cardiac adverse events, including hypertension—so based on this evidence there was no benefit for patients, just harm in adding Avastin.

The Best Treatment May Be Less Treatment

A couple of studies evaluated the provision of less treatment in an effort to reduce the harms of treatment. I took note of what Dr. Hyman Muss, (from the University of North Carolina at Chapel Hill) said: "the best therapy is not always the most therapy."

The first study looked at older women with low risk tumors. This was from the Prime 2 trial and was presented by Dr. Ian Kunkler, professor of clinical oncology at the Edinburgh Cancer Research Center. The harms of radiation are well documented and this study evaluated whether older patients with more benign tumors might omit radiation and be spared the morbidity associated with radiation treatment. Data from women who were randomized to whole breast radiation or no breast radiation after lumpectomy showed that older women with low risk breast cancer (small hormone positive tumors) who did not receive radiation with a lumpectomy were no more likely to die of breast cancer than women who did receive radiation. Only 1% experienced metastasis and the majority of deaths were not from breast cancer.

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While there is no difference in overall survival, radiation does reduce local recurrence of hormone positive breast cancer by 2.8% over 5 years: 1.3% compared to 4.1% recurrence for non-radiation. Receiving radiation upfront lowered the chance of the tumor growing back from 4% to 1% but there was no effect on survival.

Furthermore, for the relatively few women whose tumors do grow back, because they have not previously had radiation, they remain eligible for a second lumpectomy followed by radiation. In summary, this gives women (who fit the above criteria) a choice of having radiation that does not appear to compromise their survival.

Surgery for women with metastatic breast cancer was also addressed in the discussion about reduced treatment. Because metastatic cancer has spread beyond the breast, this surgery is sometimes referred to as "local control." Dr. Seema Khan discussed data related to two studies (one from India and one from Turkey) evaluating the benefit of surgery for women with metastatic disease. There were some differences in the trial design between the two studies presented. Dr. Khan noted the difficulty of designing trials given the heterogeneity of metastatic cancer and the range of systemic therapies used. Despite these variations, the key finding of both studies was no difference in overall survival for women with metastatic cancer who did or did not have surgery to remove the breast tumor.

In addition to these two studies presented, there are four additional studies evaluating this same issue that are taking place around the world. When those studies are complete, we'll need to reassess the current assumptions in light of any new data that emerges. Based on the studies presented at SABCS in 2013, surgery should not be offered to asymptomatic women with metastatic breast cancer.

Psychology and Survivorship

(For more information on this topic see the accompanying article in this issue by Zoë Christopher.)

Dr. Lesley Fallowfield (University of Sussex) works on psychology and survivorship issues. Originally a nurse before pursuing degree in experimental psychology, Fallowfield's talk at SABCS ("Psychology/Survivorship Issues: Are we doing any better?") was remarkable for her humor and humanity. Unlike so many people immersed in clinical trial data, rather than downplaying the effects of breast cancer diagnosis and treatment, she understands the "really horrible" nature of many side effects and takes seriously the question of "are we making progress?"

Fallowfield addressed two issues of survivorship: women who will go on to be cancer-free and women with metastatic disease (too often overlooked in survivorship discussions), who have equally important psychosocial needs. As more women are surviving their cancer diagnosis for longer periods, there is a growing community of women living with breast cancer.

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But “nothing comes without a cost” notes Fallowfield—and the cost of both diagnosis and treatment is substantial. Even advancements in better radiation, more chemo options, a range of hormone treatments, and new targeted therapies all take a significant toll. And these physical effects of treatment are accompanied by important psychological, social and sexual effects. All of which can be acute and long-term. While many of these effects are documented, they are themselves not adequately managed. Furthermore, “few patients inhabit social vacuums and diagnosis and treatment affect everyone else in her social milieu.”

Anxiety and depression are common among women diagnosed with breast cancer. Approximately one-third of women are likely to have experienced one or both over the disease period. But, importantly notes Fallowfield, measures of anxiety and depression were developed for psychiatrically ill, rather than physically ill, patients.

Given the implications of a cancer diagnosis, anxiety is not surprising. Women face a real risk of recurrence and metastasis, even years after the initial diagnosis. Fallowfield argues that for this reason, understanding and managing anxiety ought to take account of the fact that women diagnosed with breast cancer are in fact facing potentially life-threatening disease. To date, non-pharmacological interventions (like yoga, art and music therapy, mindful-based stress reduction, cognitive behavior therapy, aromatherapy, massage, etc.) have ebbed and waned in popularity, with mixed and modest results.

Given my personal and professional experiences supporting women through breast cancer diagnoses, I was not at all surprised that 80% of patients referred to a counselor for anxiety actually had unmet informational needs about their diagnosis rather than psychological problems. As we know more about breast cancer (and more about what we don't know), communication with patients has gotten more and more complex and the importance of patient information and decision aids is clear. Healthcare providers must ensure patients are truly educated and give informed consent—not an easy disease to explain with all the subtypes and advances in treatment options.

Fatigue has come to replace nausea and vomiting as the biggest post-cancer treatment problem and may last many years. To treat fatigue, Fallowfield argues, we must understand it. Interestingly, rest may not be the best remedy for fatigue. As several studies have shown, exercise improves mood state and fatigue, specifically aerobic exercise but not resistance training. For the debilitating problems associated with lymphedema, prevention is key. In the absence of good treatments, the onus is on surgeons to minimize the harm by doing sentinel node biopsy that dramatically reduces the rate of lymphedema from 20% to 5.6%.

The side effects of hormone therapy, vasomotor problems, and sexual problems that can occur from treatment are not just minor inconveniences—and they lead to women going off treatment. Each of these effects is often under-recognized; and if under-recognized, they are then under-reported, and as a result under-treated.

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Almost three quarters of Australian women experienced sexual problems in the 2 years following diagnosis. Eighty-percent of those women claimed they had satisfying sex life prior to diagnosis. Moisturizers are better than lubricants for vaginal dryness. Seventy-seven percent of these Australian women reported hot flashes and night sweats. In terms of non-hormonal interventions, only relaxation decreased frequency and severity.

An effect of cancer diagnosis that is rarely addressed in forums like SABCS is the economic burden on women and their families. While there is some discussion of the high costs of treatments, the broader economic impact is rarely discussed. I was surprised to learn that many women don't return to work and 10 months after surgery, that number is only 59%. With the caveat that I do not have access to her slides, I believe Dr. Fallowfield reported that the estimated economic loss for women and their families is \$16,441 in the year of diagnosis and an additional \$4,500/year thereafter.

I was so pleased that Dr. Fallowfield explicitly discussed what she called "survivorship" in metastatic breast cancer. Virtually all of survivorship focused on breast cancer neglects the issues in metastatic disease. Yet there are clear and unmet psychosocial needs. About half of women reported difficulty talking to others, and denying the severity of their illness to close friends and relatives. Inability to work presents major challenges and has a huge impact on families. Frequent medical appointments produce additional strains.

One area that is discussed is the physical and psychological impact of bone metastasis, which is often painful and not effectively treated. My own focus on inequities brings me to add that African American women are at particular risk for inadequate pain control, as research has shown their doctors are more likely to suspect drug dependency.

Dr. Fallowfield concluded by addressing the discomforts of treatment and the impact of time spent traveling to and from endless medical appointments as well as the time waiting to be seen. She discussed ways of changing treatment protocols to minimize this time as well as the discomfort of IV treatments.

After all, time is precious for all of us, whether we are living with metastatic cancer or not.

Activating Science: How the Environmental Breast Cancer Movement is Shifting Science for the Better

By Vanessa Raditz, BCAction Member

Editor's note: This article is based on an interview Vanessa did with Dr. Rachel Morello-Frosch, a Professor in the departments of Public Health and Environment, Science, Policy, and Management ---at University of California – Berkeley. Dr. Morello-Frosch is currently working on a study of breast cancer



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in female firefighters in the San Francisco Bay Area who are regularly exposed to chemicals in smoke. This study is a partnership with Silent Spring, United Fire Service Women, San Francisco Firefighter Cancer Prevention Foundation, Commonweal, and Breast Cancer Fund. She was interviewed by Vanessa Raditz in winter 2013 for this article.

2014 has been yet another big year for the environmental breast cancer movement. With the ongoing battles against hydraulic fracturing (fracking) and the industry-sponsored Chemicals in Commerce Act, the fight for sane policies that prioritize human health over corporate profit is far from over. For years activists in the environmental breast cancer movement, like Breast Cancer Action, have been calling out the limitations of breast cancer awareness and treatment and the need to focus on primary prevention of breast cancer by eliminating its root causes. Activists have worked tirelessly to build a movement that amplifies and empowers real human voices and experiences, and this has had far-reaching impacts, including how scientific research is conducted. In fact, U.C. Berkeley Professor Rachel Morello-Frosch believes “the environmental breast cancer

movement has really shifted scientific lines of inquiry.”

Morello-Frosch explains that the traditional model of breast cancer research asks a very limited set of questions about the causes of breast cancer. “We are realizing that genetics, lifestyle, when you have kids, your weight, if you drink, all of that kind of stuff - much of which we as women have very little control over – maybe at best explains about 20% of breast cancer cases,” she says, even though these areas have been the focus of research for decades.

To explore the remaining 80% of breast cancer diagnoses, activists point to the tens of thousands of chemical pollutants in our environment that we know little about. Yet, research methods in the study of environmental health have not provided information about environmental chemical causes of breast cancer at the speed and to the depth that are needed to combat this epidemic.

The environmental breast cancer movement has long urged more researchers to think outside the box of traditional breast cancer research. “Breast Cancer Action has been a big part of this [shift], . . . as well as other organizations that have cared about environmental links,” Morello-Frosch told me.

Thanks to activists pushing a progressive breast cancer agenda, there are now new methods, questions, and approaches to working on environmental causes of breast cancer. The evidence emerging from these lines of inquiry is strengthening the call for a precautionary



Dr. Rachel Morello-Frosch at BCAction's 20th anniversary celebration, where we honored her work researching the environmental links to breast cancer.

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principle, an approach that shifts the burden of proof back onto the industries that pollute, and away from the people who pay the price with their health and lives.

Upstreaming the science: Designing studies that look at earlier impacts

Innovative new research methods are picking up the pace and examining how chemical exposures from a very young age may impact the early signs of breast cancer later in life.

Traditionally, many scientists interested in the links between exposures to environmental toxins and diseases such as breast cancer have relied on research methods from the field of epidemiology, a type of public health research that looks at the associations between exposures and diseases over large populations, and often over long periods of time.

Morello-Frosch explains that this is an extremely inefficient research model for breast cancer because “by the time you’ve made a link between an exposure and a disease, you need a lot of cases. You need a lot of dead bodies to make that link.”

Because cancer can take so long to develop, and the causes could come from many different sources, some of them beginning very early in life, epidemiology is simply ineffective at establishing the necessary links to chemicals of concern.

Instead, Morello-Frosch and many other researchers, such as those at Silent Spring Institute, a research institute established by the activist group Massachusetts Breast Cancer Coalition, have turned to methods in toxicology and exposure assessment.

Toxicology looks at the health impacts of different doses of chemicals in animal studies. Many studies from this research model have shown that there are an abundance of chemicals in the environment that act as mammary carcinogens, such as the hundreds of endocrine disruptors in household products.

Exposure assessment, meanwhile, assesses chemicals to which people are actually exposed. One way of performing this assessment is examining biomarkers of exposure: signs of chemicals in people’s blood or other body tissues, like breast milk. These exposures can then be linked to biomarkers of disease: early biological signs that help predict the development of cancer before it happens. Focusing on early biomarkers of disease means that scientists can get results and propose interventions before study participants actually develop breast cancer.

Morello-Frosch explains how this shift in methods is a vast improvement for environmental health research. “Rather than spending a long time demonstrating links [between chemicals and disease]” she says “a more effective route, is to quantify people’s exposures to these hazards and then to see what you can do about it.”

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Bio-monitoring, non-targeted approaches and Community-Based Participatory Research

Of the thousands of chemicals in industrial production that end up in the air we breathe, the water we drink, the food we eat, and the products we use, only a handful have been very well studied. New approaches to research are attempting to cast a wider net outside of these “known chemicals of concern” to identify more of the chemicals that are working together to create diseases like breast cancer.

An increasing number of studies look directly at the chemicals in people’s bodies, a process known as “biomonitoring.” A recent report from the National Health and Nutrition Examination Study (NHANES) looks at about 300 chemicals. Yet this is a small fraction of the thousands of chemicals in widespread use. Morello-Frosch explains the problem of such limited scope studies: “If you are deciding beforehand what you’re testing for, you may not necessarily be picking chemicals that people have very high exposures to, or you could just be studying the same things over and over again.”

Today, more researchers are moving away from this “targeted approach” towards a “non-targeted approach” that requires collecting samples, running tests, and developing a series of molecular profiles that can be compared to a database to identify the full array of chemicals that might actually be in someone’s body.

The benefit of such an approach changes the research. “Your sample is telling you what’s in it instead of you telling it what you’re going to look for,” Morello-Frosch explains. “This reveals different kinds of exposures that people might not have thought about.”

This non-targeted approach has revealed more endocrine-disrupting chemicals in people’s bodies—a class of chemicals that has been one of the most important recent discoveries in the study of the environmental causes of breast cancer, but until recently were not being studied at all.

Non-targeted approaches may also prove to be a better method for addressing the life-long, multiple, cumulative exposures that people face in real life. All of the chemical pollutants in the toxic soup that surrounds us interact with each other in the body. These interactions may have even more profound impacts on human health than do individual chemicals.

In addition to non-targeted approaches, the movement towards Community-Based Participatory Research (CBPR) is an important shift in research methods, giving scientists more perspective on the causes of breast cancer. This innovative research model (used by Morello-Frosch) emphasizes building authentic relationships with the community and enables researchers to better understand what is important to the communities their work will impact. In addition, this approach makes researchers accountable to a given community.

By looking at the broad range of chemicals communities are actually exposed to, combined with the diligent work of activists pushing for transparency and involvement in the science that

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impacts them, researchers are now finding better methods to examine risks for breast cancer, in ways that improve the science.

Stress, poverty and racism: Exploring how injustice is carcinogenic

The questions researchers ask when designing their studies have been changing as well. Over the past decade, studies have increasingly focused on the impacts of stress and psychosocial factors in breast cancer: how poverty and racism get under the skin and become illness and disease. There has been movement within the study of environmental health science to expand the definition of “exposure” to include the very real and measurable impact of stress hormones in the body in response to these socioeconomic factors.

Researchers like Morello-Frosch attempt to measure stress in the body and assess how it interacts with the many other cumulative exposures to chemical pollutants. This is a new frontier in exposure science, and researchers looking at this are currently developing and comparing methodologies.

“We want to measure exposure biologically, through things like stress hormone levels and their impacts,” says Morello-Frosch, “and we want to measure it by interviewing women and getting their perceptions of stress exposure, and . . . looking at external factors like characterizing their neighborhoods based on census information about where they live.”

Major research programs are involved in this initiative. As Morello-Frosch explains, “the California Breast Cancer Research Program is trying to open up new lines of inquiry into looking at non-genetic reasons for why we might see different kinds of cancer among African-American women,” who are more likely than their white counterparts to develop the disease younger, be diagnosed at a later stage, and to have triple-negative breast cancer, a subtype that is more difficult to treat. Studying how stressors such as racism aggravate or contribute to the development of breast cancer shifts us away from the problematic focus on race as genetic-difference, and towards more socially-conscious conclusions that call for the elimination of discrimination and the systemic social causes of illness.

Stress is not the only injustice in breast cancer. People living in poverty and people of color often live closer to highly polluting industries, have jobs that put them in contact with hazardous chemicals, and have difficulty accessing foods without pesticides or other chemical concerns. Morello-Frosch pays attention to the many diverse ways people living in poverty are disproportionately exposed to chemicals of concern. For instance, “there’s a very interesting paper that came out that showed that people who had relied on food banks had higher levels of BPA,” she says, “probably because they are eating a lot of food from cans.”

Science re-fueling activism: Awareness is not prevention

New research methods coupled with the growing body of evidence linking environmental exposure to breast cancer is fueling demands for policy interventions that hold industry accountable for eliminating toxic chemicals.

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Research supports the fact that policy intervention is imperative to address and end breast cancer because simple awareness of the problem is not enough to eliminate exposures that fuel the disease. "In the work that I have done," says Morello-Frosch, "biomonitoring has revealed that even among very environmentally-aware people, who work their butts off to avoid toxic products, when you do the biomonitoring, they are still exposed to chemicals. Our personal ability to control exposures is limited no matter how wealthy you are, or how much you know."

This new line of breast cancer research, fueled by activists, has in turn fueled the work of activists seeking stronger regulation of toxic chemicals. The Toxic Substance Control Act (TSCA) of 1976, the outdated and ineffective law that is supposed to protect us from toxic chemicals, has been long overdue for reform. This bill grandfathered into circulation thousands of chemicals whose health impacts we know nothing about, and TSCA has a limited track record for regulating old and new chemicals alike. Finally, thanks to a combination of new research and ongoing activism, TSCA reform is now on the national agenda.

The growth of innovative research methods points to the overwhelming inefficiency of the current process of proving chemicals unsafe decades after they are released into the toxic soup that fills our environment and our bodies. Researchers share activists' frustrations of having to prove that a chemical has caused harm when our regulatory system fails to require that they be proven safe.

The recently proposed Chemicals in Commerce Act similarly fails to provide a precautionary approach that would shift the burden of proof towards industry to prove the safety of the chemicals they put into the world and our bodies. Nor does it protect communities who are most impacted by toxic exposures, even though scientific evidence clearly indicates that some people and some communities are more impacted by chemical pollutants than others.

Despite this progress, scientific research alone does not create the policy change that we need. Change must be leveraged by researchers, communities and activists at every level throughout the country in order to be effective.

Morello-Frosch cautioned that researchers are still scratching at the surface in developing these new study designs, and that "it's going to be awhile before we get definitive answers." Science will always be a slow process of change and refinement. Science's quest for exactness is its strength in the policy arena, but it is also its weakness when it comes to immediate matters of life and death.

Nevertheless, thanks to the push from activists, breast cancer research is moving towards improved methods for study design that will reveal more chemicals of concern, work through cumulative chemical interactions at even earlier stages of development, and possibly detect biomarkers of disease before breast cancer even emerges. This information can now be used to push back against unethical industry-supported legislation like the Chemicals in Commerce Act.

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The loud, defiant, and empowered voices coming out of activist organizations like Breast Cancer Action have long been catalyzing these conversations between science and policy to promote policy interventions that take a strong precautionary approach. "They are saying, we can't sit around and wait for science," says Morello-Frosch.

Science and activism are in continuous states of co-production, and when effectively linked, make for a powerful team.

Vanessa Raditz is a Breast Cancer Action member and Master of Public Health Candidate at U.C. Berkeley, studying issues related to cumulative impacts, connections between human and environmental health, and participatory science for achieving environmental justice.

Breast Cancer's Inconvenient Truth

By Scorchy Barrington. Scorchy is a breast cancer advocate who blogs at The Sarcastic Boob.

When I was first diagnosed with Stage II, Grade 3 invasive ductal carcinoma in July 2012, I experienced a surprising sense of entitlement. It was strange, really, as I paid scant attention to the whole breast cancer movement and have an inherent cynicism of large self-perpetuating organizations of any kind (of which there are several in the breast cancer field). I didn't even know that October was "Breast Cancer Awareness Month," (Good job blowing all that money on awareness!) yet I still wanted my breast cancer perks. Were there not special programs for me now? Was I not supposed to have been given pink notebooks and pink notepads and pink ribbon pins and breast cancer pens? Was I not automatically enrolled in a local support group?



I was ashamed of this line of thinking. How could I have been swept up into a pink slumber party when I would otherwise ignore this kind of nonsense? I'd just received some pretty sobering news, yet my overriding thought was getting pink disease swag. Maybe, I thought, I was just in denial and trying to find the least offensive way toward acceptance of my diagnosis. I wanted to be OK, so I just assumed that I would have surgery, chemotherapy, radiation, and then I would re-enter the world. I set myself a timetable of 18 months to move through the disease to the point where I could be a survivor. That was the way it was supposed to work, right? It was a rite of passage, I told myself. I would see cancer as a blessing, walk all over the country raising awareness (because you can't have too much), and give other women pink shiny things.

Three weeks into my breast cancer diagnosis I learned that the cancer had metastasized. I knew then that, far from my optimistic 18 month timetable, breast cancer would now always be with me. Breast cancer would kill me.

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I realized with some embarrassment that I had allowed myself to be manipulated by a persistent and insidious message of commercialized breast cancer survival. But the worst part about it? There was no room in that message for me or others like me who are living with and dying from metastatic disease. Even in the month of October, where every single day is devoted to breast cancer awareness, one could only talk about metastasis for one day. So on Friday October the 13th we get to talk about death? Nice.

Pink ribbon breast cancer marketing has trivialized breast cancer, and metastatic disease is breast cancer's inconvenient truth that doesn't fit into the cheerful pink narrative. Of those who have ever had or have breast cancer, 30% of them will develop metastatic disease. 100% of people who die from breast cancer die from metastatic disease, so you'd think it'd be a high priority. Yet despite this number, only 2-3% of funding goes to research that focuses solely on metastasis. For all of the success of the breast cancer movement over the last thirty years, those with metastatic disease are conspicuously absent.

One organization, METAvivor, has made it their "raison d'être" to encourage 30% of funds raised in the name of breast cancer to go towards metastatic research, to match the 30% of people with metastasis. METAvivor's 2012 campaign "The Elephant in the Pink Room" rightly named metastatic disease as the proverbial "elephant in the room" when it comes to breast cancer. METAvivor has long encouraged the discussion of metastatic breast cancer in all discussions of this disease because with awareness and discussion come the needed funds for research. METAvivor's message accompanying the "Elephant in the Pink Room" campaign was simple and clear: Don't Ignore Stage IV.

So you can imagine my own surprise and the surprise of many people when we found out last month that the national department retail chain, Kohl's, in conjunction with Susan G. Komen (no longer "For the Cure") was running a fundraising campaign calling breast cancer "The (Pink) Elephant in the Room." Complete with a pink striped elephant (no teddy bears here!) and happy fonts, Kohls' campaign implored us, "Don't Ignore It. Breast cancer is the (pink) elephant in the room and we need to talk about it" with nary a mention of metastatic disease. Komen, in this case, continued its practice of creating "breast cancer awareness" built on the backs of individuals with metastatic disease. Only this time they did it by coopting the campaign of an organization that donates 100% of the funds it raises to metastatic research. Two wrongs do not make a right. They never do.

Breast cancer has been trivialized, sexualized, and feminized to the extent that "cancer" is all but removed from its identity. In the pink zeitgeist, we get to live beyond five years as a survivor or we are "remembered." In a very cruel and surreal sense, in the world of pink those of us with metastatic disease are worth more dead than we are alive.

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Welcome to our New Board Member Jasmaine Williams

In January 2014 we welcomed a new member onto our Board of Directors. We are excited to introduce you to her.

My name is Jasmaine Williams and I am currently working on a PhD in Cancer Biology at Stanford University. I also completed a Master's degree in Medicine in March 2012. I am originally from Georgia, and majored in Biology and Spanish as an undergraduate at the University of Georgia in Athens. I have been in California for the past four years after moving from Georgia and love living on the West Coast!

I had previously volunteered with a variety of organizations and events focused on breast cancer, particularly in the African American community. As someone who studies breast cancer in an academic environment, I wanted to work with an organization based in California that I felt was truly effecting change in the breast cancer community. Breast Cancer Action fit this requirement perfectly! After reading about the organization and meeting all of the incredible women who have been a part of BCAction over the years, I am humbled and excited to serve as a member of the Board of Directors for the organization.

I love the fierceness of Breast Cancer Action, and how we are completely unafraid to challenge the status quo of commercializing a disease that affects so many lives. Through groundbreaking efforts such as Think Before You Pink® and working on the Supreme Court case to challenge the patenting of human genes, I am inspired by the consistency and clarity of BCAction's mission. As a younger member of the Board of Directors, I'm also proud of the efforts we are making to be inclusive as an organization and to bring in new perspectives to comprehensively tackle this epidemic.

I am most looking forward to using the different aspects of my own identity as a catalyst for unifying voices in the breast cancer community. It is critical for women to understand why we are outraged as an organization, and why they should be too! As a Board member, I hope to clearly communicate that message to women of all racial and ethnic backgrounds, socioeconomic status, and levels of education. I believe the most important changes in addressing the breast cancer epidemic will come from uniting people around the importance of "people before profits" in breast cancer, and I look forward to contributing to that effort as a part of Breast Cancer Action.



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Program Department Update (November 2013 – March 2014)

Information & Referrals

BCAction's Information & Referral program continues to be a valuable resource for people who have been diagnosed or who are otherwise affected by breast cancer. Between November 2013 and February 2014, we responded to over 90 inquiries from people on, as always, a variety of topics including the side effects of taking Raloxifene or Arimidex for more than 10 years, the dangers of cell phone use, taking Arimidex to lower risk of recurrence in elderly women, and chemical policy reform.

San Antonio Breast Cancer Symposium

BCAction attended the San Antonio Breast Cancer Symposium in December 2013 to bring a patient-focused voice to the proceedings, to challenge the status quo, report findings back to you, and to push researchers and clinicians to do better for women at risk of and living with breast cancer. Get updates on treatment here as well as a report-back about psycho-social issues facing women with breast cancer here.

Webinars

BCAction's webinars allow members to get a deeper understanding of key breast cancer issues paired with opportunities to take action. If you missed our most recent webinars, they are all archived on our website and available to view here:

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

"The Ecology of Breast Cancer" with Ted Schettler, MD, MPH (Feb 2014)

"FDA Approval: Who's Being Harmed and Who's Being Helped?" (March 2014)

Breast Cancer Screening

In December, we submitted comments to the U.S. Preventive Services Taskforce (USPSTF) regarding their proposed research framework that will lead to updated mammography screening guidelines. You can read the summary of our comments on our blog.

In February, new research, this time from Canada, once again questioned the value of screening mammography in the general population. This study found no reduction in mortality among women diagnosed with breast cancer that had been found with or without mammography. Breast Cancer Action immediately went into action raising our longstanding concerns about the lack of clear benefit to the use of mammography for screening (as opposed to diagnostic). This issue of The Source features a response to the study by the chair of our Board of Directors, Tracy Weitz.

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California's Proposed Pink Ribbon License Plate

California Assemblyperson Joan Buchanan introduced AB49 which, if enacted, would create a pink ribbon specialty license plate in California. Breast Cancer Action has expressed concerns about this bill, including that the proposed messaging is misleading and inaccurate. As it stands now, the plate would read, "early detection saves lives" which is especially problematic given the recent Canadian mammography study published in February 2014 in The British Medical Journal! In addition, funds generated by sales of the pink plate only go toward screening and not follow-up treatment, care or counseling for low-income women. BCAction has engaged with Representative Buchanan over the past several months regarding this issue and this winter we stepped up pressure to improve this bill.

In December, we sent a letter to Buchanan's office, once again expressing concerns regarding AB49. This letter was signed by leaders in the breast cancer community in California, including Karuna Jaggar, Executive Director at Breast Cancer Action; Peggy McGuire, Executive Director at Women's Cancer Resource Center; Sara O'Donnell, Executive Director at Cancer Resource Centers of Mendocino County, and Maria Caprio, Director of Shanti's Margot Murphy Breast Cancer Program.

In January, along with Peggy McGuire from the Women's Cancer Resource Center, we sat down with Assemblyperson Buchanan to discuss changing the message on the proposed pink plate. Our next steps involve working with the Women's Cancer Resource Center and other allies to identify and propose alternate messaging to ensure that the pink plate is not promoting inaccurate information about breast cancer screening.

Kohl's Pink Elephant Campaign

pink elephant
In February, we were outraged when we discovered Kohl's department store marketing a "Kohl's Cash for the Cure" program. This program, a partnership with Susan G. Komen, was yet another example of corporations making money off breast cancer via pink cause marketing. Kohl's donated \$1 million to Susan G. Komen – but that means shoppers had to spend \$50 million at Kohl's. Breast cancer sure is good for the bottom line! The campaign's messaging perpetuated inaccurate information about mammography screening, and worst of all, by referring to breast cancer as "the pink elephant" in the room, co-opted the recent "pink elephant" campaign led by our allies at METAvivor to raise awareness about metastatic disease.

We called out Kohls' shameful campaign that diverted attention away from METAvivor's important work for metastatic breast cancer on our social media platforms encouraged our members to call foul on Kohl's and support METAvivor. Read more about the impact of the campaign in this issue's Member Perspective.

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Gene Patents and Genetic Testing

On June 13, 2013, the Supreme Court ruled to strike down Myriad Genetics' patents on the human "breast cancer" genes, BRCA1 and BRCA2—and not just Myriad's patents, but patents on all human genes. This was a tremendous win for women's health – and for all our health!

In the months following the U.S. Supreme Court's decision, we were alarmed to see Myriad Genetics respond with aggressive lawsuits to preserve their monopoly and keep other BRCA testing companies out of the marketplace. In August, we filed an amicus brief in federal court to express opposition to preliminary injunctions on BRCA testing filed by Myriad against both Ambry Genetics and Gene by Gene, Ltd. – two companies embroiled in lawsuits with Myriad Genetics.

Gene by Gene, Ltd. recently settled with Myriad Genetics, and we are happy to report that in early March, Myriad was denied its preliminary injunction against Ambry Genetics. While the legal landscape of this issue is far from settled, we continue to look for ways to ensure that genetic testing companies are properly serving women at risk of genetic mutations linked to breast and ovarian cancer.

Toxic Chemical Reform

During the fall of 2013 the Chemical Safety of Improvement Act (CSIA) was introduced in the U.S. Senate as a proposed update to the Toxic Substances Control Act (TSCA). Breast Cancer Action and many other health and environmental organizations opposed the CSIA for its failure to fully protect public health and safety by inadequately addressing the thousands of unregulated chemicals in our daily lives.

In March 2014, Congressman John Shimkus (R-IL) released a discussion draft of the Chemicals in Commerce Act that is even worse than the CSIA. This new proposed bill is a gift to the chemicals industry rather than a meaningful effort to protect the public from hazardous chemicals linked to a range of diseases and disorders, including breast cancer.

We submitted a letter of opposition to the Chemicals in Commerce Act to the committee charged with debating the bill, and over 1,200 BCAction members contacted their Representatives urging opposition to this bad bill. We will continue to keep the pressure on our elected representatives to reject the Chemicals in Commerce Act, and support truly meaningful TSCA reform legislation instead.

Anti-Fracking Work

In March, Breast Cancer Action endorsed and participated in Don't Frack California, the largest anti-fracking rally in state history. The rally, on March 15th in Sacramento, demanded Governor Gerry Brown ban fracking across the state.

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We know that fracking for oil or natural gas is a health hazard because the chemicals used in the process contaminate our water supply with known human carcinogens and endocrine disruptors. These dangerous chemicals enter our water supply in two ways:

First, fracking companies mix industrial chemicals with water, and shoot the mixture deep underground to free oil or gas deposits.

And second, contaminated wastewater is dumped directly into rivers and streams.

Fracking is a public health issue, plain and simple, and as advocates for women's health, we will not stand silently by and allow this dangerous practice to continue.

Community Leaders for Change

In existence for over a year, our Community Leaders for Change program (formerly the Speakers Bureau) continues to support and train women across the country to serve as leaders about breast cancer issues in their community by facilitating discussions and providing education and outreach at health/community fairs, house parties and other community events. In November, we reached out to all 31 women who have been involved with the program since its inception to conduct a one-year program evaluation. We thank all the respondents and look forward to incorporating their feedback to improve the program. 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.

10th Anniversary of Billie Gardner Loulan Memorial Celebration Filled with Music, Laughter and Community

This spring, former member of the BCAction Board of Directors, JoAnn Loulan, hosted the 10th Anniversary Billie Gardner Loulan Memorial Celebration in Portola Valley, CA.

Ten years ago, event chair JoAnn Loulan was already older than her mother, Billie Gardner Loulan, when Billie died of breast cancer. JoAnn said, "I was determined not to die as she did. Inspired by her bravery and activism, I wanted to honor her



JoAnn Loulan and her partner Ronny Crawford

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memory." The Billie Gardner Loulan Memorial Luncheon benefitting Breast Cancer Action was born.

There are not enough words to express the depth of our gratitude for all that JoAnn has done to support and inspire all of us at Breast Cancer Action. JoAnn is a truly remarkable woman whose passion, joy and sheer determination have changed the world. JoAnn touches the lives of all of us lucky enough to be part of her community as she asks us to join her in making the world a better place. From the bottom of our hearts, thank you, JoAnn, for your ten years of service to BCAction. Here's to another ten, plus.

The Portola Valley community was welcomed into the beautiful home of our gracious event hosts, Debbie and Andy Rachleff. This celebratory evening event was filled with music, laughter and community.

While noshing on delicious savory and sweet fare, guests were entertained by the dynamic and funny couple, former Saturday Night Live actor Paul Barrosse and Victoria Zielinski. They dazzled us with their comical and musical hijinks, and brought relevancy and urgency to the live auction and the "Fund a Need" to fund BCAction's work.

Grammy®-nominated singer/songwriter, Lisa Loeb performed a memorable acoustic set specially tailored for this event. Crowds swooned as she sang her platinum-selling #1 hit song "Stay (I Missed You)" from the film Reality Bites, as well as tunes from her album "No Fairy Tale" which was named one of the Best Albums of 2013.

Supporter Spotlight: Ryan & Chris Haigh

***Editor's Note:** Ryan and Chris Haigh are brothers who launched a fundraising campaign this year that raised over \$30,000 for Breast Cancer Action. We are so grateful for their generosity and the generosity of their community. Sarah Harding, our Development Director, asked Ryan and Chris about the campaign and what inspired them.*

SH: What was your inspiration for the "Beards for Boobs" campaign?

Chris: Our mom has the BRCA gene mutation. When she found out about her diagnosis, she planned to have a prophylactic mastectomy. During that time, she was diagnosed with breast cancer.

Ryan: My brother and I were tested for the gene mutation as well and Chris tested positively. We have a large Italian family and we are really close and cancer has affected so many of our



Ryan (left) and Chris with their mom

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family members. We were tired of having people we love taken away from us and tired of just talking about cancer. We wanted to do something that showed how much we appreciated our mother and her strength.

As we thought of ways to take action, I was reminded of a fun family memory. When I was little my dad grew a beard. I loved it and thought it was so rugged. For fun a few years ago, my brother Chris and I decided to have a three-month long “beard-off” with our dad. The camaraderie and friendly competition that my brother and I felt during this beard-off with our dad gave me the idea for doing a beard-off with our closest friends to raise money for a breast cancer organization doing good work.

SH: Can you tell us about your fundraising campaign?

Ryan: Chris and I began by reaching out to 65 of our closest friends to ask if they would participate in a two-month long beard-off to raise money for breast cancer. Everyone starts out with clean-shaven baby faces, which creates conversation in itself that lends nicely to starting a conversation about why we are doing it. It gives it a fun aspect. Each participant was asked to grow their beard for the entire two months. During this time, people reached out to family and friends to ask them to support them by making a donation to Breast Cancer Action. At the end of the two months, we had an event to celebrate and show off our beards.

Ryan: We didn’t think it would be as successful as it was. We raised over \$30,000 for BCAction! We were amazed at how many people got involved. We really appreciate our friends but we never expected so many of them to come together and work together in this way.

Chris: I had people walking up to me at work to tell me how they were personally affected by breast cancer. I didn’t know how many people I knew were affected. It gave the whole thing a purpose. It excited me to be part of something bigger than myself.

SH: What inspires you about the work of Breast Cancer Action?

Ryan and Chris: We looked around quite a bit to find the right breast cancer organization and we were very selective about which organization we approached. The Pink Ribbons, Inc. documentary was a huge part of what inspired us to choose Breast Cancer Action. We felt it shined such a light on the issue. We wanted to support an organization that approaches the breast cancer epidemic differently than mainstream organizations.

Ryan: There are so many negative views on breast cancer fundraising. Some people tell me that they didn’t want to support our campaign because they felt breast cancer is over-funded. I think they feel this way because many organizations aren’t approaching the disease as an epidemic. Until I saw the documentary, I had no idea that this was happening. Breast Cancer Action’s former executive director Barbara Brenner was amazing in the film and I wanted to support her vision and the work BCAction is doing. We like that BCAction is doing it differently. You have our full support moving forward.

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SH: How did you come up with the name – Beards for Boobs?

Ryan: Chris' co-worker came up with the name. The name is a sensitive point because we don't want people to think we are making a joke of the disease. Seeing what our mother went through was not a funny thing. I asked my mom and she asked her support group for their opinions on the name of our campaign and they supported it. The name has not offended people but people have questioned it.

Chris: The upside to the name is that there is alliteration and it speaks to the goofy nature of the 65 guys who are involved and helped make it successful but we want to be smart about it going into year two.

SH: Do you have plans for the future?

Ryan and Chris: Yes! We now have time to plan for next year so we are energized and want to blow this year's campaign out of the water. The first year was just the beginning. We only tapped into 10 percent of our resources. The possibilities are limitless.

Special Thanks: Spring 2014

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

Erika Luger – much appreciation for your help with our strategic planning process.

Alan Kleinschmidt and the **San Francisco Choral Society** for continuing to feed our souls with complimentary tickets to their fabulous performances for our board, staff and volunteers.

Susan Karp, Sara Brandon, Rhea Flores and Julie Morgan for answering many last minute calls for assistance with projects in the office.

Sara Brandon for her ongoing administrative help.

Sarah Rocklin for her willingness to share her expertise and to help out wherever needed.

Ted Schettler, Science Director of the Science and Environmental Health Network, for his engaging and informative presentation on February's webinar "The Ecology of Breast Cancer with Ted Schettler, MD MPH.

Diana Zuckerman, President of the Cancer Prevention and Treatment Fund of the National Research Center for Women & Families, for her wonderful presentation on March's webinar "FDA Approval: Who's Being Harmed and Who's Being Helped?"

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Vickie Williams for her energy and commitment to our Community Leaders for Change program representing BCAction at the Hampton Roads Marketplace Enrollfest in Hampton, VA on March 7th.

Michelle Garcia for her time and energy as a Community Leader for Change representing BCAction at the 13th Annual Allison Taylor Holbrooks/Barbara Jo Johnson Breast Cancer Conference in San Francisco on March 1st.

Valerie Deering for organizing two more Pink Ribbons, Inc. screenings in Merriam, KS on Feb 18th and Kansas City, MO on Jan 15th.

Ryan and Chris Haigh for organizing and inspiring 65 fundraisers who raised over \$30,000 dollars for Breast Cancer Action through their Beards for Boobs campaign.

10th Anniversary of the Billie Gardner Loulan Memorial Celebration

Event Chair: JoAnn Loulan

Jennifer Crawford

Event Hosts: Debbie and Andy Rachleff

Jenn Meyer

Julie Morgan

Entertainment:

Phenomenal live auction and comedy duo,

Paul Barrosse and Victoria Zielinski

Special musical performance by Lisa Loeb,

accompanied by Ronny Crawford

Erin Parsons-Wright

Armin Staprans

Amy Washburn & daughters

Vendors:

Weir Catering & Event Planning

Michael S. Hensley Party Rental & Sales

Scotty Dog Sound

Event Sponsors

Julie Goldman & Bob Rosner

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Ginny Kavanaugh

Karen Klein & Ben Golvin

Suzanne & Jim Kohlberg

Tashia & John Morgridge

Lee Ann Slinkard & MariaMorris

Alison Superko & Brian Mills

Karen Tate

Susan Valeriote & Ken Goldman

Plumblin Coaching and Consulting

A very special thank you to the group of donors who helped raise over \$62,000 by participating in a generous matching grant opportunity by the Laurel Foundation!

Jan Avilla

Janice Brody

Susan Brown

Claudia Cappio

Cathy Carlson

Diane Carr

Nancy & John Cassidy

Maryann Derwin

Joanne Donsky

Donna Dubinsky

Mary & Emily English-Freeman

Kathy & Robert Feldman

Invitation and Graphic Design: Amber

Ramies

Event Volunteers:

Sinead Corwin

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Pan Haskins
Sheryl & Anthony Klein
Suzanne & Jim Kohlberg
Laurel Foundation
Sally Lillis
Sharon & Mark Lockareff
Gardner Loulan & Liz Miracle
JoAnn Loulan & Ronny Crawford
John & Susie Loulan
Brett Mangels
Wendy McPherson & Djuna Woods
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Julia Louis-Dreyfus
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SalonJoshua Ets-Hokin Photography
Good Vibrations
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Seeing Red: The Truth About Pink Ribbons

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Linda Burnett
Beverly Canin
Terry Holzman
Ngina Lythcott

Emcee:

Callie Crossley

Panelists:

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Donations in Honor and Memory: Spring 2014

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 IN HONOR

BCAction gratefully acknowledges donations made in honor of the following individuals between November 5, 2013 and April 2, 2014.

All of My Friends With the Disease from Elizabeth Merck	Joyce Bichler and Michael Kimbarow from Carl and Elaine Coelho
Laura Anderson from Rebecca Pinto	Alison Braverman from Vicki Green
Geva Arcanin from Margo L. Arcanin	Jill Brown from Nancy and Richard Curtin
Tina Barnes from Betsy Aubrey and Steve Lichtenberg	Eve Borenstein from Karen Strauss
BCAction's newsletter, <i>The Source</i> from Eva and Daniel Langton	Ruth Borenstein from Karen Strauss
Deborah Behrakis from Carole L. Mendelsohn	Susan Burdett from Allyson Johnson
Jamie Bezole from Karen Strauss	Carol from Kimberly Heim
Joyce Bichler from Anonymous from Denise and Todd Helfstein from Marcia and Alan Kimbarow from Lucille Saks from Arlene and Robert Stams	Natalie Compagni Portis from Beverly Portis Deb from Karen Klein and Ben Golvin

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from Karen Strauss

Jean Hardisty
from Amelie Ratliff

Coon Family
from Anonymous

Katanya Henry
from Barbara J. Attard

Susan Fine
from Robert Clark

Irma Hypes
from Denise Holmes

Janet Frost
from Gail and Barry Kaufman

Alison Jaggar
from Beverly Canin

Elena Fuentef-Afflick
from Trinidad Madrigal

Karuna Jaggar
from Judith A. Patrick

Roberta Gelb
from Roy Nachowitz

Kara Guzzetti
from Peter Guzzetti

Dorothy Geoghegan
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Catherine Jonas
from Melissa DeBenedetto

Lori Leigh Gielegem
from Karen Merritt

Gwen Kibbe
from Janet Phillips

Thelma Ginnis and Michele DeTunno
from Annita Ginnis

Kirsten
from Karen Klein and Ben Golvin

Trudy Goldau
from Sharon Goldau

Kathy Klos
from Anonymous

The Athey Grandchildren
from Coral J. Fry

Susie Lampert
from Lorie Nachlis and Abby Abinanti
from Kyra Subbotin and Henry Siegel

Amy Halio
from Suzi Goldmacher

Linda's mom
from Erica Bigelow

Kerri Hamernick's mom
from Julie Morgan

JoAnn Loulan
from Jayne Mordell
from Diane Mosbacher and Nanette
Gartrell
from JoAnn Ogden and Janet Luce

Sarah Harding
from Pat and Randy Demuri

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from Mary Orbe
from Bonnie and Andrew Sterngold
from Lisa Troedson

My Sister
from Kathleen Dunckel

Tracy Lutz
from Tiffany Boyle

Nikki
from Karen Klein and Ben Golvin

Many Friends
from Alice Lowe

Juanita Sanchez
from Jennifer Molina

Rosie Madrigal
from Trinidad Madrigal

Sandra Park, Skadden Fellow
from Skadden, Arps, Slate, Meagher
&Flom LLP

Martha
from Karen Klein and Ben Golvin

Polly
from Karen Klein and Ben Golvin

Barb Martinez
from Dave Patriarche

Franny Posner
from Fran Danoff

Me!
from Beth Blevins

Nancy Poyourow
from Carole Poyourow

Hilde Meislin
from Barbara J. Meislin and Stuart Kaplan

Raya Sass Rubin
from Julia Rubin and Gregory Stankiewicz

Nesanel Mitiku
from Lisa Harbus

Madeleine Severin
from Judith Goldberger

Rachel Morello-Frosch
from Karen Strauss

Elana Silver
from Tami Wallenstein

Julie Morgan
from Jo Ann Morgan

Rachel Silvers
from Anonymous

Lori Morton
from Robert D. Morton

Jocelyn Sobieraj
from Janet and Jerome Sobieraj

Myself
from Alison Braverman
from Anonymous

Dorian Solot
from Suzanne Miller

My Husband
from Nancy Fitzpatrick

Kyra Subbotin
from Laura Enriquez

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Rochelle Wunsch
from Barbara Wunsch

Linda Zumwalt
from Anonymous

Cindy Zimmerman
from Tiffany Boyle

Patti Zussman, for her birthday
from Lois Zussman

DONATIONS IN MEMORY

BCAction gratefully acknowledges donations made in memory of the following individuals between November 5, 2013 and April 2, 2014.

Pat Anesi
from Anonymous

Annie V.
from Corky Wick

Rita Arditti
from Estelle Disch
from Barbara Rubin

Linda Baralt
from Mary Lorraine Carson

Annie Barr
from Harry A. Blanton

Dorothy Becker
from Elizabeth M. Becker

Blanche
from Corky Wick

Joy Bol
from Anonymous

Barbara Brenner
from Anonymous (2)
from Diane Beeson and Donald Warrin
from Sandra Blair

from Lawrence Brenner and Roderic
Hooks
from Mark Brenner
from Richard and Barbara Brenner
from Cheri Bryant
from Tiffany Boyle
from Susi and Donald Cell
from John Connolly
from Estelle Disch
from Nancy Davis and Donna Hitchens
from Glikman Associates, K. Glikman,
M.C. Duboscq, J. DeLa
from Bruce Gold
from Julie Lynn Goldman and Robert M.
Rosner
from Nanci and Donald Grail
from Irma D. Herrera and Mark D. Levine
from Nickie Hilbert
from Lisa Honig and Dale Schroedel
from Leonie and Glen Janken
from M. Anne Jennings
from Susan Laskin
from Mary Law
from Kelly Moran
from Carolyn Nelka
from Deborah and Peter Nelson
from Kathleen J. Purcell
from Tom Reilly and Kevin James
from Belle Shayer
from Megan Silverman
from Karen Stevenson and Bill McClave

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from Margaret Stevenson and Karen Topakian
from Susan and Robert Vanneman
from Lisa Westerback
from Laurie J. Woodard
from Stan Yogi
from Jane Sprague Zones and Stacey Zones

Leslie Brenner
from Diane and Edwin Bernbaum

Betty J. Brown
from Cheryl Wilson Stevens

Darcy Bryant
from Mark Ewell

Selma Butter
from Marsie Scharlatt

Shirley Camden
from Sarah Douglas

Terry Chauche
from Lisa Westerback

Rachel Cheetham Moro
from Mary Goldman
from N. John Lombardi

Cherrie
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Laura Cole
from Miriam Stombler and Kevin Kelem

Elena Cross
from Sandra Cross

Jean S. Davis
from Nancy Davis and Donna Hitchens
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from Lee Ann Slinkard and Maria Morris

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from Sallie Jones

Donna Drabble
from Laurie Drabble

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Susanne Duerden
from Sandra Cross

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from Anonymous

Rosalind Lambert Easley
from Gail B. Gough

Miriam Eng
from Tonia Wolf

Karen D. Ennis
from Nancy Davis and Donna Hitchens

Beth Joseph Ervais
from Julie Becker

Ellen Lew
from Anonymous

Pat Folan
from Barbara and Alan Krause

Phebe Frank
from Lisa Westerback

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BCAction gratefully acknowledges online donations made in honor of the following individuals between November 5, 2013 and April 2, 2014.

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from Wendy Mnookin

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