Historic gene patent case and rally at Supreme Court

By Karuna Jaggar, Executive Director

Every day, I talk to our members, donors, and partner organizations from across the country by phone and in person. It’s a favorite part of my job and a critical piece in my understanding of how our work matters for you. Recently my conversations have gotten particularly energetic when we turn to our lawsuit challenging Myriad Genetics’ patent on the human BRCA 1 and BRCA 2 genes, the so-called “breast cancer genes”.

On April 15th our case comes before the U.S. Supreme Court, which will consider the question: Are human genes patentable? I believe this is one of the most important and wide-reaching issues Breast Cancer Action has taken on.

In 2009 Breast Cancer Action filed suit in this landmark case against Myriad Genetics when no other breast cancer organization—many of whom need Pharma and Biotech friendship and funding—would touch it. Under our former executive director Barbara Brenner’s leadership, BCAction joined researchers, genetic counselors, and patients challenging Myriad’s patent on the BRCA genes because human gene patents create a barrier to progress on breast cancer and harm women’s health.

Myriad Genetics’ claim on our very DNA creates a profitable corporate monopoly for them, generating approximately half a billion dollars a year in revenue. In the last fiscal quarter alone, Myriad made $126 million off genetic testing for breast cancer—a full 85% of their total revenue.

But while Myriad is making billions, human gene patents stifle desperately needed research and innovation in breast cancer, and create real harm for women at risk of and living with breast cancer. We cannot afford to let corporate profits come before patients. Not when nearly a quarter of a million women will be diagnosed with breast cancer this year. Not when around 40,000 women will die in the coming year.

Everyone I talk to is initially shocked and puzzled to learn that one company, Myriad Genetics, holds a patent on human genes. How can a corporation claim to own a naturally occurring part of your and my essential genetic code?
I believe they can’t. And I am proud to stand with you, partner organizations, and women’s health activists in taking a stand to outlaw human gene patents. On April 15th, while the Supreme Court is hearing oral arguments, many of you from across the country will be joining Breast Cancer Action for a rally to outlaw human gene patents on the steps of the Supreme Court.

It has been fun to receive the excited texts, tweets, and emails rolling in day and night from members, donors, and partners who are lending their time, money, and voices to this critical issue. I am looking forward to standing shoulder to shoulder with many of you who will join us on the steps of the Supreme Court. I’m also energized by the many ways those of you who can’t join us in DC are showing your support: spreading the word, writing blogs and op-eds, and donating to support this work.

BCAction has been working for five years for this moment to take a stand against corporate control over our genes, our health, and our futures. Thank you for standing with us, and all they ways you are taking action on this critical women’s health issue.

**Q&A With Sandra Park About Upcoming Gene Patent Case**

We asked Sandra Park, a staff attorney with the ACLU Women’s Rights Project and one of the lead attorneys in our case against Myriad Genetics’ patents on the “breast cancer genes,” to answer a few questions about this landmark case. The case is *The Association of Molecular Pathology, et al v. Myriad Genetics and will be heard by the Supreme Court on April 15th*.

1. Why did the ACLU decide to take on a legal challenge to human gene patents? Can you explain how this is a civil liberties issue?

This is the first patent case ever brought by the ACLU, so we studied the issue closely and consulted with many people before deciding to get involved. Ultimately, we realized that gene patents, and the policy of the U.S. Patent and Trademark Office of granting these patents, must be challenged because of the important civil liberties concerns they raise. Gene patents stand in the way of scientific innovation and medical care because they allow the patent holder to lock up all possible uses of the gene. Nobody can examine, study, or develop anything based on the gene without permission from the patent holder (in this case, Myriad Genetics). As a result, gene patents undermine scientific inquiry and freedom, bodily integrity, and particularly in the case of the BRCA1 and BRCA2 genes, women’s health.
2. What are the potential outcomes of this case, both in the U.S. and globally? Could this case invalidate all human gene patents?

If the U.S. Supreme Court invalidates the BRCA patents, that ruling will impact the validity of the many other, similar gene patents that have been issued. It is estimated that 20% of human genes have been patented, including genes associated with colon cancer, Alzheimer’s disease, and muscular dystrophy. Countries around the world often take cues from the U.S. patent system and so the ruling could influence other countries’ policies as well.

3. What is the crux (in layperson terms) of the case against patenting human genes?

For over a century, the U.S. Supreme Court has said that products and laws of nature cannot be patented. Our case simply asks the Court to apply this precedent to human genes.

Myriad argues that it somehow invented the BRCA genes once it "isolated," or removed, the genes from the rest of our genome. By that logic, we should grant patents on iron once removed from rock, or on a kidney once removed from the body for transplant.

Myriad was the first to identify the link between mutations on these genes and breast cancer. It made an important contribution to scientific knowledge. But it defies law and common sense to force the public to rely on a single company to fully investigate the wide range of scientific, medical, and commercial uses of something as fundamental to our health and humanity as a gene. We see the consequences already: labs across the U.S. are ready to offer patients more comprehensive, lower priced testing for cancer risk than Myriad provides, but cannot include the BRCA genes in their tests because of the patents.

4. Would you describe this case as landmark or historic? If so, why?

This is a landmark case, for many reasons. Foremost, this is the first case ever brought challenging whether human genes can be patented. The answer to this question will have a huge impact on the future course of medicine and scientific research. Second, it is a case brought by a diverse group of twenty plaintiffs, including Breast Cancer Action, patients, geneticists, and scientific professional associations. The commitment of the plaintiffs demonstrates that patent law is not just about one company versus another; patents affect real people, with real consequences for how patients access medical care and what clinical standards and research are pursued. Third, the case highlights how some patents can stand in the way of scientific advancement, in violation of the U.S. Constitution’s requirement that patents “promote the progress of science.” Permitting monopolies on individual genes runs contrary to the constitutional purpose of our patent system.
Round-Up From San Antonio Breast Cancer Symposium 2012

By Karuna Jaggar, Executive Director

The San Antonio Breast Cancer Symposium is the largest breast cancer research conference in the world, with attendees from over 100 countries, where the newest study results and research is often announced. We report back from San Antonio from a patient advocate perspective, challenging the status quo and pushing researchers and clinicians to do better for women at risk of and living with breast cancer. Below you can read Karuna’s reports from the 2012 conference in case you missed any.

Lower Dose Radiation: Reports From the START and TARGIT Studies

Arguably the clearest practice changing standard to emerge from the 2012 SABCS conference is the long-anticipated data supporting shortening the duration of radiation therapy after surgery. The results of the START trial were discussed by the British Dr. Yarnold during the General Session on Thursday and again at the morning Plenary Lecture on Friday. Already the UK has adjusted their standard of care based on this data.

This year important 10 year follow up data was presented from the UK START (or Standardization of Breast Radiotherapy) trial, which looks at varying schedules and doses of radiation. Five year results were presented in 2008 and showed that a shorter, more intense dose of radiation had similar outcomes to the current standard US dose. This follow up analysis looks at 10 year data, which is important given the fact that adverse effects of radiation generally arrive late (after 5 years) and the importance of ensuring that anti-cancer effects also last.

The fundamental issue with radiation dose is identifying ways to be gentle on normal tissue but not too gentle on breast cancer—which would have no advantage. Indeed, as Dr. Yarnold noted, because tumors are not somehow more sensitive to radiation than normal tissue, the concern is that a lower dose to protect healthy tissue may not have the desired effect on the tumor. The START trial evaluates this question.

The study treated women with early breast cancer (stage 1-3 operable disease). The relatively simple design randomized women into two groups:
• Arm A used the standard dose and duration in the US: 50 Gy [note: I cannot explain radiation doses which are “fractionations” and am simply reporting this aspect of the trial without further explanation] over 5 weeks (25 days)
• Arm B increased the dose to 40 Gy and shortened the duration to 3 weeks (15 days)

Median follow up of data presented was just under 10 years. Primary outcome to be evaluated was recurrence in the area of the original tumor and additional endpoints included local regional relapse and secondary endpoints included disease free survival, overall survival and effects on normal tissue (including patient self reported outcome, independent assessment of photographs, etc.)

Long term outcomes of both arms were equivalent, with suggestion of better cosmetics (less breast hardening and shrinkage) in the shorter “Arm B”. Furthermore, acute effects of radiation were more tolerable with shorter duration (despite higher dose) of radiation with regard to skin damage.

The findings of this trial support higher dose, shorter duration radiation therapy which has now become the new standard of treatment in the UK, treating for 3 weeks at 40Gy (as opposed to 5 weeks at 50 Gy as currently done in the US).

It is worth noting that this data is not entirely new—although the long term data presented is important. There has been a migration toward this trend in the US but it has been a slow migration. Several radiologists noted that the primary barrier to changing is the current method of reimbursement for radiation therapy, which is to bill by the week. Thus this move to shorten treatment would effectively remove 2/5 (or early half) of a radiation oncologist’s revenue from each individual breast cancer patient.

One argument frequently provided against higher dose, shorter duration is cardiac toxicity. There is no safe dose of radiation for the heart: the total dose is the issue and the heart needs to be protected during radiation. Dr. Yarnold gave a cost-free, drug-free, toxic-free solution: if a woman takes in a deep breath and holds it during the 40 seconds or so of radiation, the air in the lung creates a space which protects the heart (without additionally exposing the lung).

One commentator noted that once the door is open to start evaluating shorter courses of radiation, there may be uses for existing radiotherapy techniques that are not currently used in breast cancer such as intensity modulated radiotherapy or image guided radiotherapy. Currently targeted machines used in head and neck cancers are too expensive for use in 5 week series for breast cancer but may become options if the dose is increased and duration shortened. As always, the doctors will seek to push it to the limit – how large a dose for how short a time?
Indeed the results of the TARGIT trial looked at single dose in the operating room—or in radiation oncologist jargon to give a sense of the SABCS experience, “single fraction delivered to the resection cavity”.

The TARGIT trial stands for TARGeted Intraoperative radio Therapy and uses a device, which was developed for brain tumors. It provides a single large dose of radiation in the operating room delivered directly to the tumor cavity for 25 minutes after tumor removal. This was compared to the standard external beam radiation therapy.

Thirty-three centers in 10 countries participated in the trial, which started in Europe but included Australia and the US. Patients who entered had generally good prognosis but the study included younger women.

Scientific rationale for TARGIT is that despite the fact that breast cancer is frequently multicentric—meaning there are multiple lesions of different size in multiple locations of the breast(s)—most recurrences happen near the original tumor. So the researchers decided to target radiation to the tumor bed.

The majority of data was just under two and a half years (median follow up 2 years 5 months). While there was not a difference in local recurrence at follow up, the likely number of events in that short duration is low enough that it will take more time to fully evaluate.

There was a reduction in overall mortality for the TARGIT group and the researcher claimed that TARGIT’s benefit is in reduced cardiac mortality even though there is slightly higher recurrence.

However, Dr Crownover expressed surprise at reported significant improvement in mortality, suggesting it is a statistical fluke related to the short time of follow up. He noted that most secondary malignancies develop after 5 years and acute effects of radiation also typically have later onset. Furthermore, there was no observed connection between left and right sided events, which put into question the plausibility of a protective mechanism related to cardiac mortality.

The take away, based on START protocols in the US should be revised to the higher dose, shorter duration UK standard on which the trial was based. It is vital, as always, that patient interest and well-being is not compromised because the current reimbursement for radiation therapy means this new protocol will represent nearly a halving of revenue. There may be additional studies further shortening the duration and increasing the dose of radiation therapy but, for now, the data on TARGIT is too short to say much with any confidence.
The Azure Trial – Vitamin D, Zoledronic Acid, and Thoughts on Menopause

Advocates have been calling out for many years for studies of non-toxic and complementary therapies. Ann Fonfa, founder of the Annie Appleseed Project made several public pleas at this year’s conference.

The closest thing we saw this year was the AZURE trial, which, although not the primary focus of the study, found that Vitamin D levels were correlated with relapse of early breast cancer.

The study included 3,360 women with Stage II and Stage III disease. Women were randomized to standard therapy or standard therapy plus zolodronic acid (a bisphosphonate marketed under trade names such as Zometa, Reclast) for 5 years. All patients received Calcium and Vitamin D supplements for 6 months and thereafter at the discretion of the physician.

The data on zolodronic acid was presented last year and there was no difference between the control and treated arms. However a planned subgroup analysis found some benefit for menopausal women (whether natural or induced) in the treatment arm who had slightly better overall survival and disease free survival.

The research presented this year aims to explain that study result by identifying ways of knowing who is more likely to experience bone metastasis, markers for who might benefit from zolodronic acid, and classify menopausal status using reproductive hormones rather than the presence of a period.

The researchers found that Vitamin D levels, rather than bone turnover, were predictive of metastasis. AZURE was a UK study and the researcher noted that just 10% of the population in the UK have sufficient levels of Vitamin D at the time of diagnosis. [With my British ancestry, I couldn’t help note that there are several sources of Vitamin D, of which sunshine is one—and of course Britain is legendary for it’s lack of sun.] The relatively few women with sufficient levels of Vitamin D appear to have much better prognosis.

The problem is that we don’t really know what “low” and “adequate” levels of Vitamin D are—if you change the cut off, you can influence what percent of the population is low, etc. There was comment that the study started in 2003 and speculation that the recommendation at the time of 400 IUs of Vitamin D is now probably not sufficient. And we have seen other studies where large doses of vitamin supplements have harmful results.

Nor are there immediate clinical lessons or ways of applying these findings. We don’t know if the form of Vitamin D makes a difference—is a supplement (vitamin pill) as good as sunlight, food, etc.? Furthermore, what about threshold and timing?
This is a hypothesis generating study and does not establish a true causal relationship nor a way to address the issue. Fundamentally, we don’t know anything about the mechanism linking Vitamin D to breast cancer even with this data from AZURE. It joins a small number of studies and some lab data that suggests breast cancer is worse in a low vitamin D environment. We don’t know if it’s the Vitamin D itself or if it’s a reflection of something else that is important. And most importantly of all, we don’t have data to suggest that replacing Vitamin D will change outcome.

One final note on the AZURE trial is that it’s difficult to compare clinical menopause to biochemical menopause because menopause is not predictable or stepwise and it takes several years. This means that physical symptoms of menopause do not always match levels of reproductive hormones associated with menopause. As Dr. Hope Rugo of UCSF said, commenting on the trial, the only true way to know if a woman is not menopausal is if she is having periods, but the absence of periods is not at all clearly the indicator of true menopause.

So, once again, this study gives us much intriguing information but mainly points out how much we still don’t know and need to learn before making any definitive conclusions.

**Disparities Poster Session – Is This All There Is to Share?**

Early Friday morning I attended a poster session titled simply “Disparities.” I expected such a broad topic would have a lot of posters. Imagine my surprise when I arrived to find just 5—yes, that is F-I-V-E—posters on the topic of disparities and breast cancer.

The first two posters were on the all too common issue of breast reconstruction rates with one focused on disparities in the use of reconstruction by a range of factors and the other looking at reconstructive surgery rates among lower income women in France. A third poster looked more broadly at breast surgery, finding that some populations are more or less likely to undergo mastectomy versus lumpectomy.

I have sat through too many presentations where the stated goal is to get more women to opt for immediate reconstruction, with the presenter diligently listing the benefits for women and bemoaning the fact that a few women opt for delayed reconstruction. The fact that choice of surgery and specifically immediate reconstruction accounted for more than half of the posters on disparities was nonetheless shocking. What about the pressing issues of cancer incidence, mortality and morbidity?

Let me say simply, the goal of ending disparities should not be simply higher rates of reconstruction. Removal of barriers to the surgery, rather than the surgery itself, must be the goal.
So I walked past those as well as a fourth poster looking at the role of patient navigation in overcoming barriers experienced by Latinas with abnormal mammograms.

I stopped at the last poster with the title “Significant Clinical Impact of Recurrent BRCA1 and BRCA2 Mutations in Mexico” by Dr. Cynthia Villareal-Garza (Instituto Nacional de Cancerologia, Mexico) and Dr. Luis Herrera (City of Hope). This study is interesting both because of the focus on risk in an underserved population and because of Breast Cancer Action’s work challenging Myriad Genetics’ patent on the BRCA genes. Studies among breast cancer patients in Mexico have shown an earlier onset of disease and a high prevalence (23%) of triple negative breast cancer. The researchers have developed a low-cost, quick screening tool which can be used to screen Mexican and Mexican American women for one particular BRCA mutation, which occurs in high frequency.

One must remember that there are hundreds of BRCA mutations, some of which are linked to an increased risk of breast and ovarian cancer, some of which are not linked to an increased risk of cancer, and some of which are unclear and the significance of which in terms of cancer risk is as yet unknown.

Based on the prevalence of one particular recurrent BRCA1 mutation, which comprises around 10% of BRCA mutations in a Mexican American sample, the researchers believe they have identified the first documented founder mutation originating in Mexico nearly 1,500 years ago.

The researchers developed a low-cost 114 BRCA mutation panel to test for the most common mutations in women of Mexican ancestry. They call their tool HISPANEL and use it to pre-screen women, saving significant cost. For women with positive mutation results, the next step is a partial (and significantly lower cost) screening test from Myriad to confirm mutation status.

More research remains into the sensitivity of the HISPANEL, whether this mutation is associated with particular tumor characteristics, etc. Nonetheless, this provides the possibility of a cost effective screening tool which can be used specifically with women of Mexican ancestry to predict risk and related screening and prophylactic options for both breast and ovarian cancer.

Having commented on the specific studies in the poster session on disparities, I must say that identification of disparities does nothing in and of itself to establish and test interventions to address and reverse these inequities.

After my disappointment on the scope of the posters, I will move on now to the very excellent discussion and comments on the poster session. Although focus on a traditionally underserved community is a part of the disparity picture, I was most excited by the fantastic comments offered by Dr. Amelie Ramirez at the UT Health Science Center at San Antonio, discussing the complex interlocking factors that affect health disparities. This was followed by comments...
from Dr. Dawn Herschman from Columbia University Medical Center. [Note: for the purposes of this discussion, I will for the most part use the presenter’s language of disparities, rather than Breast Cancer Action’s preferred language of inequities.]

Dr. Ramirez began with the reminder that disparities, as defined by the National Cancer Institute, include a wide range of adverse difference in incidence, prevalence, deaths, survivorship, burden of cancer or related conditions among particular populations. While it is widely recognized that race and ethnicity are tied to different health experiences and outcomes, it is worth remembering that age (both the old and very young), gender (which may include LGBT), income, education, insurance status, culture (including histories of exploitation) and disability (whether physical/mental disability or comorbidity) are all factors affecting specific population groups. So called underserved populations who experience health disparities are not a homogeneous group.

These factors that are related to disparities are interconnected and interlock in important ways, visually demonstrated in a series of slides with interlocking gears that connect a range of factors important to disparities. Having a disability can impact the ability to work and therefore impact insurance access. Culture interacts with survivorship issues, language barriers, etc.

These and other factors interact in ways that are hard to navigate while dealing with cancer. Being low income may mean that a patient lacks childcare during medical visits, is unable to pay for services and medications, lacks transportation, can’t afford not to work, etc.

We know that women of color are more likely to die of breast cancer and cancer deaths are declining fastest among white women. Non-white women often have more aggressive cancers that are harder to treat, coupled with fewer social and economic resources. Differences in screening, follow up, treatment, and survivorship all demonstrate inequities in quality of care.

Here I will veer from Dr. Ramirez’ comments. It is not enough to identify the breadth and depth of these disparities, we must focus on interventions to reduce these inequities. Having discussed the complex and interlocking nature of the factors related to disparities, interventions that focus on simple outreach, scheduling support seem to offer a mere band aid. More coordinated support which provides case management, and advocacy, still seems doomed to only partially treat the problem. We believe we need to get at the root causes of these inequities to make lasting change.

As Dr. Ramirez concluded: “Cancer health disparities are multi-causal and involve many factors from diverse sources.” It is not enough to target simply specific disparities, she further notes: “We must also focus on the general causes of inequalities.”

Dr. Dawn Hershman further added to the conversation by noting that poor quality care can result from too little care, too much care, and the wrong care—overuse, underuse, misuse.
Dr. Hershman further notes that determinants of care go beyond the individual determinants (race, income, age, culture, literacy, insurance) and include also physician determinants (training, social networks, personal preferences, etc.), hospital determinants, (hospital type, investment in medical technology, patient mix, etc.) and county/state determinants (health care spending, physician supply, etc.).

In directly targeting specific inequities, one must identify the modifiable factors: whether place, insurance, health literacy, access to specialists, beliefs, cultural sensitivity, etc.

With the complexity of the issues regarding inequities in breast cancer, I hope next year we’ll see many more posters on this topic, including ones that go well beyond the focus of breast reconstruction. These studies are needed to add to our understanding of the many issues of huge importance in this area.

**Racial Disparities in Sentinel Node Biopsies**

At SABCS last year, in 2011, one of the memorable moments was when Dr. Laura Esserman from UCSF stood at the mic after a presentation and publicly pleaded with all the surgeons in the room to abandon routine full lymph dissection. The data on which she was commenting resolved once and for all that sentinel node biopsy should be the standard of care, providing sound diagnostic and prognostic data while improving quality of life by decreasing rates of lymphedema.

At the time, I suggested this was not news. Indeed sentinel node biopsy—a procedure in which the sentinel lymph node is identified, removed, and examined to determine whether cancer cells are present—has been the preferred technique for a number of years, since around 2007.

At this year’s symposium, Dr Dalliah Black presented data doing a retrospective analysis of the SEER/Medicare database studying over 31,000 women diagnosed with invasive breast cancer between 2002 and 2007 who did not have lymph node involvement and underwent a documented axillary surgical procedure.

The data shows that African American women are approximately 12% less likely than white patients to have sentinel node biopsy, thus exposing them to a more invasive surgery with higher complications, including risk of lymphedema. White women were more likely than other races to get the preferred sentinel node biopsy: 74% of white women compared to 65% of other races and 62% of African American women.

Possible reasons suggested for this disparity include lower socioeconomic status of African-American patients, less access to health care, and differences in tumor biology. However the 12% disparity held true even adjusting for a range of factors.
We know that African American women, while less likely than white women to be diagnosed with breast cancer, are more likely to die of the disease. In addition to higher mortality, African American women have higher morbidity associated with the disease. They are more likely to experience worse side effects. The result of this disparity in surgery is that African American patients have double the rate of lymphedema.

This study documents the disparity but does not provide us with a full understanding of the reasons and mechanisms by which race is an independent variable linked to sentinel node biopsy. Nonetheless, Dr Black suggests that when implementing new standards of care and practice-changing recommendations, it is important that education and outreach to practitioners happens to ensure that all patients benefit from advances in treatment.

**Tamoxifen for 5 or 10 years? Results From the ATLAS Study**

With not enough progress on breast cancer, patients and doctors alike are eager for the next best thing. Today at SABCS there was a lot of trumpeting that the next best thing is here! It involves Tamoxifen. And although I’m as ready as anyone for a breakthrough, we know from experience we have to look beyond the headlines for the real story on “groundbreaking” breast cancer news.

Tamoxifen is an anti-estrogen drug given to women with hormone sensitive breast cancer to prevent spread and recurrence. Used widely for more than two decades, tamoxifen is relatively cheap and has been available in generic form for 10 years. Tamoxifen remains the standard treatment for approximately two-thirds of breast cancer patients with estrogen sensitive breast cancer.

Current protocols recommend five years of tamoxifen which has been shown to reduce death from breast cancer by approximately one-third. Earlier studies in the 1990s suggested that extending tamoxifen beyond five years not only increased toxicity but also produced worse outcomes for women on ten years of tamoxifen.

Today the results from the ATLAS study were reported. ATLAS—which stands for Adjuvant Tamoxifen: Longer Against Shorter—is a worldwide collaborative trial started in 1996. Nearly 7,000 women (6846) women with hormone sensitive (ER+) breast cancer were enrolled in a dozen countries. Just over half of the women (54%) had no lymph node involvement. This large study looks for small differences in the risk of recurrence and death for women who take tamoxifen for five years versus ten years.

Tamoxifen is unusual in that the beneficial effects persist for a number of years after stopping treatment; such that five years of tamoxifen brings an extended benefit for an additional five years. In order to evaluate ten years of tamoxifen, any potential benefit of this longer
treatment must be compared to the known extended benefit of five additional years of benefit from five years of treatment.

The ATLAS results show, and the media widely trumpeted, that doubling the length of time women take tamoxifen does reduce the risk of recurrence and death. Just over one in five women who took the longer ten-year course of tamoxifen experienced a recurrence (21.4%) compared to one in four (25.1%) women who took the current five year standard. This amounts to an absolute difference of 3.7%. More importantly, 12.2% of women in the ten year arm died from breast cancer compared to 15% of women in the five year arm, an absolute difference of 2.8%. The researchers noted that the benefit was mainly seen after ten years, with relatively little effect in years 5-9 when the two arms of the study (five vs. ten years) saw similar outcomes.

The toxicity of tamoxifen is well known. Not surprisingly, doubling the duration of tamoxifen also doubles the risk of endometrial cancer (from 1.6% to 3.1%) and death from endometrial cancer (from 0.2% to 0.4%). Additionally there were more blood clots although not more fatality as a result of the blood clots. The presenter confidently calculated “there is a 30x benefit versus the risks” of extending tamoxifen.

Yet as many patients and patient advocates know, the risk and benefit that matter to women don’t always show up on presentation slides at conferences. Quality of life issues factor in heavily to women’s decision to continue treatment or not. Approximately 30% of women discontinued tamoxifen treatment early because of side effects and quality of life issues. We know that some patients are so miserable on tamoxifen that even a 3% reduction of disease or death is not enough to tip the balance for women. One doctor on the panel discussion that evening acknowledged: “It’s all I can do to get some patients to take [tamoxifen] for five years. If life is miserable, you have to weigh benefits and risks.”

Despite what you read in the media, some patients and doctors attending the conference are not so sure that more is, in fact, better when it comes to tamoxifen. The question is: does the relatively modest benefit warrant the additional treatment? And if so, which women may choose to extend tamoxifen? Several doctors in an evening discussion insisted that the data do not necessarily make the case that everyone should take tamoxifen for ten years. Recognizing the significant quality of life issues from tamoxifen, the question is: what is the level of risk that would warrant a woman signing up for five more years of tamoxifen? While ER+ breast cancers tend to have better prognosis, younger women are at higher risk and (knowing they are ineligible for aromatase inhibitors) perhaps they might be recommended additional years of tamoxifen. Furthermore, women who can’t tolerate the side effects of aromatase inhibitors may consider extending tamoxifen treatment.

I’m eager for the next best thing, and I’m still waiting.
Breast Cancer Action Takes on Fracking’s Health Harms

By Annie Sartor, BCAction Policy and Campaigns Coordinator

Introduction

Last fall, a short article published in a small town Oklahoma newspaper caught our attention. The article described an oil and natural gas drilling rig that Oklahoma-based Nomac Drilling had turned pink in honor of breast cancer “awareness.” We were aghast. We’d seen many instances of pinkwashing, but this was especially egregious.

Nomac Drilling and their parent company, Chesapeake Energy, are among the biggest natural gas producing companies in the country. They routinely use hydraulic fracturing (“fracking”), as a method of extracting ever more oil and gas from deep within the earth’s surface. We know that over 700 chemicals are commonly used in the process of drilling and fracking for oil and gas, including dozens that are listed as “chemicals of concern” because of their link to multiple health harms. Benzene, Acrylamide, Ethylene Oxide, Bisphenol A, formaldehyde, lead, and Di (2-ethylhexyl) phthalate are all known carcinogens or endocrine disruptors that are widely used in the fracking process and have proven links to breast cancer. The idea that Nomac Drilling would turn pink a drilling rig used in a process that could expose people to harmful chemicals linked to breast cancer motivated us to take action.

We sent a letter to Chesapeake Energy’s CEO demanding that the company, along with all of its subsidiaries, commit to not using chemicals of concern that are linked to health risks, including breast cancer, in any of its operations. If they care so much about breast cancer, they shouldn’t introduce chemicals linked to the disease into the water we drink and the air we breathe. When we didn’t hear back from Chesapeake Energy, we asked you, our members, to take action. Nearly 2,000 Breast Cancer Action activists wrote to Chesapeake, asking them to stop pumping poisons into the earth and into our bodies. Our work is by no means over. In fact, this is just the beginning. Fracking is an inherently dangerous process, and the industry is growing. We have to demand an end to fracking across the country and stop cancer before it starts.
Fracking is a Threat to Public Health

Hydraulic fracturing is the process of taking millions of gallons of water, mixing it with tens of thousands of gallons of chemicals, including known carcinogens and endocrine disruptors, and pumping the mixture deep below the earth’s surface with extreme pressure to break up rock formations and release oil or natural gas.

Once underground, the chemical/water mixture can leach into the water supply and impact people living nearby whose well water may be contaminated. But its reach doesn’t end there—toxic chemicals have been found in nationally-distributed food, produce (even alcohol) grown on land contaminated by fracking. Additionally, contaminants from fracking find their way into the faucets of faraway cities once they seep into the water table. Fracking is not just a small town, rural problem; the impacts of this grossly under-regulated industry are widespread.

The fracking process exposes us to known carcinogens and endocrine-disrupting chemicals. But because companies refuse to release comprehensive lists of chemicals used (they consider them “trade secrets”), it is impossible to pinpoint which chemicals are used by any individual company or at any specific operation site. Companies engaging in fracking refuse to take responsibility for, or even acknowledge, the public health risks involved. The fracking industry is grossly under-regulated and poses a fast-growing threat to public health.

The Time to Act is Now

Fracking is a booming business right now—it enables oil and natural gas companies to extract more fossil fuels than they otherwise could. Low natural gas prices, coupled with a society with ever-increasing energy needs, mean that demand for fracking is sky-high. Energy companies are expanding their reach across the country and staking claim to wells as part of a mad rush to start pumping chemicals into the earth—all in an effort to extract oil and gas from the earth as quickly as possible.

In response to the fracking boom, a movement of organizations and individuals has come together to challenge the devastating consequences of this practice. Environmental organizations, public health organizations, land-owners and community groups are working regionally in areas where fracking is ongoing. In order to pro-actively protect human health and the environment, this movement is now organizing on a national level to demand moratoriums or bans on fracking before the practice becomes even more prevalent.

Breast Cancer Action is proud to take our place in this movement against fracking, and as so often happens we are one of the only health organizations currently involved. We are driven by our belief in the precautionary approach to public health: if an action or policy has a
suspected risk of causing harm to the public or to the environment, then the burden of proof rests with those taking action to demonstrate their actions will not harm public health. There has been no comprehensive study or analysis to prove that fracking is safe. Instead, there are many reasons to believe that fracking causes harm to human health, including increased risk for breast cancer. We cannot and will not wait until hundreds or thousands of women die to take action.

**Breast Cancer Action’s Fight against Fracking**

We have long been committed to stopping cancer before it starts, in addition to supporting women diagnosed with the disease, and to do so we need to stop cancer-causing toxins from entering our world and bodies in the first place. Fracking is part of this work to create healthier environments for all of us. As a breast cancer organization long concerned with the impact of unregulated toxic industries, without corporate funders to appease or please, we can bring a strong feminist public health analysis to the movement against fracking.

Since last fall, we have already made significant contributions to the movement to stop fracking. We called out Chesapeake Energy and Nomac Drilling’s pinkwashing in November and began to educate breast cancer activists across the country about the impacts of fracking. In December, we became a founding member of the Americans Against Fracking coalition – a national coalition of over 100 environmental, civic, health, and business organizations that are coordinating a national strategy to ban fracking. We also signed on to state and national letters to legislators demanding bans on fracking and helped expand the reach of the anti-fracking movement to women living with and affected by breast cancer.

We will continue to grow our leadership role in shaping national anti-fracking strategy and we will do more to highlight examples of pinkwashing by fracking companies like Chesapeake Energy and Nomac Drilling.

We look forward to mobilizing you, our members, to write letters to the editors of local, regional and national newspapers, to give testimony at hearings where fracking regulation is under consideration, and to urge elected officials to outlaw this practice that is bad for our long-term health.

We are keeping our eyes and ears open to new and promising opportunities. The movement to end fracking is building momentum now, and we are looking forward to playing an important role in protecting women, and all people, from the inherent health risks that fracking poses. We hope that you will join us.
Making Room in the Breast Cancer Narrative: Social Injustices and Health Outcomes

By Sahru Keiser, BCAction Education and Mobilization Coordinator

Do a Google search for “breast cancer risk” and you’ll find a lot of information about obesity, diet, alcohol, and genes. What you won’t find – very easily, at least – is information connecting where we live, work and play, and how society treats us as people, to who gets breast cancer, at what age, and how likely they are to die from it.

Race and class inequities in breast cancer outcomes are not solely the fault of low screening rates, limited access to healthcare, or individual “lifestyle choices” – though that’s what the mainstream narrative would have you believe. The elephant in the room is the reality that inequities in breast cancer incidence, mortality and survival stem from a complex interplay of social and economic factors, including power dynamics, race/ethnicity, and discrimination. Yet to read the news, or mainstream breast cancer websites, you’d think there’s a magical eat-right-exercise-maintain-a-healthy-weight silver bullet to resolve the grossly unequal health outcomes between white and non-white, poor and rich.

We cannot continue to let the dominant narrative about breast cancer – and our health in general – leave out or footnote important social and economic factors that have a very real impact on our health. Here are some recent examples of how these factors play a role in the breast cancer epidemic:

At the end of last year, the Center for Disease Control and Prevention (CDC) released a report analyzing breast cancer incidence and mortality data from 2005-2009. They found that although breast cancer death rates for women in the U.S. are declining, not all communities are benefiting. African-American women now have a 41% higher breast cancer death rate than white women, which has been rising since the 1980s. While the CDC attributed this difference to lower rates of screening and less access to care, it also stated that there is “a substantial part of these differences [that] remains unexplained.” So it seems that factors such as racism and discrimination, language and cultural barriers, “fenceline communities” (poorer neighborhoods, predominately communities of color, located immediately adjacent to industrial facilities) and occupational hazards fall into the “unexplained” category.

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Earlier this year, the December 2012 edition of the Journal of Cancer Survivorship, published an article on “Racial and ethnic differences in health status and health behavior among breast cancer survivors—Behavioral Risk Factor Surveillance System, 2009.” According to this study examining racial and ethnic differences among breast cancer survivors, researchers concluded, yet again, that surviving breast cancer comes down to what you do as an individual, and that interventions promoting healthy lifestyles are key. This article, however, failed to mention the social context in which women make choices about their behavior. We know that different communities have different social advantages or disadvantages that determine the options they have to make healthy choices. As long as we continue to tell people to make better choices without increasing access to resources, we continue to set women up for perpetual failure and we continue to blame them for their disease.

The Atlantic recently published a very interesting article by Jason Silverstein about how racism affects our health. “How Racism Is Bad for Our Bodies” focused on stop-and-frisk policies and the impact racism and discrimination – and even anticipated racism and discrimination – has on the health of people of color. The article notes that discrimination has been shown to increase the risk of stress, depression, the common cold, hypertension, cardiovascular disease, breast cancer, and mortality. Social epidemiologist Nancy Krieger, one of the field’s leaders, terms negative health outcomes as a result of discrimination “embodied inequality.”

Silverstein writes: “Racism works in a cycle to damage health. People at a social disadvantage are more likely to experience stress from racism. And they are less likely to have the resources to extinguish this stress, because they are at a social disadvantage.” So we begin to see how our individual choices are not apolitical, and do not occur in a vacuum. As the article points out, this “embodied inequality” can be generational: “These are ways that discrimination becomes embodied during one person’s life. But no person discriminated against is an island. When conditions of social injustice affect this many people, and prompt poor health outcomes, risk passes down generations. And this damage isn’t going away any time soon. Even in the absence of discrimination, Nancy Krieger argues, populations “continue to exhibit persistent disparities reflecting prior inequities.”

If we really want to address inequities in breast cancer and end the epidemic, we need to make room in our breast cancer narratives for the inextricable link between social and economic factors to our health, factors such as race, power and neighborhood resources, as well as the structural barriers that prevent too many communities from receiving high quality healthcare.
Breast Cancer Action continues to challenge our society’s strong and over-simplified emphasis on personal behavior as the silver bullet. We believe that effective strategies to eliminate inequities and reduce disparities in breast cancer incidence, mortality and survival, require a broader focus on the social and economic contexts in which we all live. Until the dominant narrative changes, we’ll keep working to change this conversation about breast cancer as we have so many others.

Welcome to Our Newest Board Member: Julie Morgan

We’re excited to introduce you to the newest member of our Board of Directors, Julie Morgan, who joined the Board in November. We’re recruiting new members right now — you can learn more on our website: www.bcaction.org.

Tell us a little about yourself prior to becoming a new BCAction Board member.
I’ve been living in San Francisco for ten years and work as an orthopedic nurse. I’m from Massachusetts originally, and I moved around growing up and continued to move around as a travel nurse – I worked on three month assignments around the country. My favorite places to live after all that traveling: Seattle in the summer and Denver in the winter and San Francisco year-round.

What brought you to Breast Cancer Action?
I was diagnosed with breast cancer in 2011 at the age of 37. Last year, after attending a screening of Pink Ribbons, Inc. with my breast cancer support group, I learned that Breast Cancer Action was holding a screening of the film and volunteered to help out at the event. BCAction was the first breast cancer organization I got involved with after my diagnosis and treatment. The breast cancer community is full of pink ribbon events and products and I knew I didn’t agree with so much of the pink spin on breast cancer. When I saw the movie, in which BCAction is heavily featured, I saw an organization that was speaking to me and my ideas about the breast cancer movement. I was always very aware that many of the products being sold and promoted in the name of breast cancer had ties to breast cancer itself and I was very turned off by that. I always questioned how much of the profits were actually going to breast cancer research. When you look at the prevalence of pink ribbon nonsense vs. how little headway we’ve made with breast cancer, you know there’s got to be a problem there.
Why did you decide to join Breast Cancer Action’s Board of Directors?
There are a lot of causes I care about but I’ve never been sure what my role could be. I’ve spent my whole adult career as a nurse on a medical-surgical floor and have done some volunteer work, but didn’t know if I had the skills to get involved on a deeper level. I’d been volunteering in the BCAction office for four months and the BCAction community, including the Board and staff, was very nurturing. Volunteering and now joining the board has been a great opportunity to learn about an organization I care about and contribute to its efficacy and success. BCAction is very straightforward and does not try to make cancer pretty or comfortable. I like BCAction’s strict corporate funding policy. I like that we are outspoken and unapologetic about critical breast cancer issues.

What most excites/inspires you about the work BCAction does?
I’m interested in looking at the causes of breast cancer; I’m all for curing diseases but there are so many bigger problems beyond. I’ve always been interested in the health of the world and I want to see more disease prevention. To me that’s the most important thing; as someone who’s been diagnosed with the disease, I want to help stop cancer from developing in the first place.

In my view, capitalism is the biggest barrier to making more progress in the breast cancer epidemic. As long as there’s money to be made in healthcare, corporate profits will skew the issues away from our truly benefiting improved health. I’m very into complementary and integrated medicine, and I had success in healing through chemo with alternative and complementary medicines. It was an opportunity to put my own philosophies about healing into action. I felt extremely fortunate to have an overwhelming amount of support and kept myself extremely busy during treatment incorporating a variety of healing modalities. I wish every cancer patient had the financial, emotional, and physical support that I had. That’s the world I’m working for.

Member Perspectives

We asked two members who are part of our pilot Speakers Bureau program to share how they came to Breast Cancer Action, why they got involved in the Speakers Bureau, and their thoughts on breast cancer advocacy and the issues most important to them. To learn more about the Speakers Bureau program, get in touch with our Education and Mobilization Coordinator, Sahru Keiser at skeiser@bcaction.org.
Member Perspective: Lori Marx-Rubiner

I am 46 years old and originally from Chicago. I’ve lived in LA since 1988. My husband John (married nearly 25 years) is, in a word, amazing. He’s who has lifted me up, dragged and supported me not only through every minute of my cancer journey but also through all of the advocacy efforts; he’s a very good sharer! Our son Zach is 14 and is as passionate as I am about changing the face of breast cancer so that other children don’t ever have to live with a sick mom. They are my greatest blessings.

I was initially diagnosed with Stage II breast cancer in 2002. After chemo, bilateral mastectomy and five years of tamoxifen, I was “no evidence of disease” for about two years when my CA 15.3 marker started rising. We watched it go up over about 18 months before a scan indicated that I might have bone mets. A biopsy confirmed that in August 2011, and I’ve been back in treatment since then.

My introduction to Breast Cancer Action came by way of a donation made in my honor at the end of my treatment back in 2002. I didn’t think much of it, to be honest. That was until I saw what other organizations are like, how they capitalize on breast cancer sympathy, perpetuate the status quo, and do very little to focus on a cure. Many breast cancer charities, of course, focus their attention on supporting people going through treatment, and that’s really important work! But many others claim a “cure agenda,” yet fail to enact policies and fund projects that can make that happen.

I thought the Speakers Bureau would be an awesome opportunity to get the word out about how backwards and even counter-productive our “pink culture” has become. And since I like people, it was a great way for me to get out from behind my blog.

Cancer is defined by its propensity for change, and I fear that it will forever remain a step ahead of us. So while I’m not sure we’re going to cure it, I am nonetheless optimistic that we can do better. Much better. But we have to start caring more about our health and wellness than we do about our convenience. Perhaps my view is skewed by living within the cancer “bubble” but it seems to me we are seeing more and more cases, at younger ages, and more aggressive cancers. When our cancer rates in the “developed world” outpace those in other countries one has to wonder how much of this is about lifestyle. I’m not talking about blaming people for their life choices – there’s more than enough of that (just look at lung cancer!), but rather about our over-exposure to carcinogens. Here in California we have Prop 65, which requires businesses to warn consumers about known carcinogens in consumer goods, but
these carcinogens are so pervasive that businesses such as stores and markets just slap a label on the building.

I want to shout from the hilltops! I’ll speak to anyone who will listen: we’ve got to change how we approach the breast cancer epidemic! We have to be wiser about how we treat the world around us because it’s all one system and it comes right back to how we treat ourselves. As someone with metastatic breast cancer, it’s too late for me. My cancer is considered incurable; it is my life’s companion now. But by using what time I have, while my health is still strong, I hope I can empower all of us to act before this epidemic gets even worse.

Member Perspective: Teresa Peters

I was diagnosed with breast cancer in 2009, and now live with metastasis in my brain, bones, and lungs. The cancer slowed me down, but generally I am thriving, living with few symptoms, and well beyond the dire predictions of several doctors. I do a mix of conventional and “integrative / alternative” treatments, but never did the traditional cytotoxic chemo or the full deal radiation, against the advice of medical professionals and other well-meaning people. I think that conventional treatment saved my life, but the other things keep me healthy now: nutrition, exercise, limited exposure to environmental toxins, and mind-body medicine. I’ve had a pretty hard road at times, bucking the conventional system and choosing my own path. I have done a ton of research and learned a lot. I am a very well-informed patient, and take personal responsibility for my health and I own all of the treatment decisions that I make.

I was born and raised in Ohio, but lived away for 24 years — I came back here to Ohio to regroup after a failed marriage and the cancer diagnosis, and ended up staying. I’m fortunate now to have a great relationship, to be involved in my community, and to be surrounded by strong supporters.

I was originally attracted to BCAction because of the Think Before You Pink® campaign. I am offended by the commercialization of breast cancer, and I have tried (with mixed success) to explain my concerns about “pink” campaigns to friends and family. I don’t think it’s OK for a company to sell a pink product with breast cancer branding on it and give only a small portion of sales to support cancer research, let alone get away with some of the awful ingredients in the products that they offer. Pink ribbons are so often a sell-out.
I found that when I voiced my own concerns with many people regarding “pink” campaigns, my opinions met with contempt. Pink has become synonymous with supporting breast cancer patients and obviously, supporting women with breast cancer is the right thing to do. Pink ribbons are just the wrong way to go about it. I was heartened to find in BCAction an organization that was speaking my language and that understood where I was coming from and was raising the alarm about it. I feel that the sole focus of the conventional cancer system on finding a cure is misguided. It is offensive to me that toxic treatments are pushed on women so adamantly by the cancer system. It seems ridiculous to not talk about prevention, as we watch the numbers continue to rise. I liked that BCAction brings the critical issue of prevention to the table.

In 2012, when I won the Environmental Watchdog Award in Ohio, I reached out to BCAction to share what I’m doing and see if there was anything I could do to help BCAction further its work, essentially just as a kindred spirit and friend, and was asked to join the Speakers Bureau. I joined because I believe that we can all do more together than we can do alone and I want to be part of a bigger effort. I know I can learn from BCAction and the other speakers, and I hope I can bring something of value to the group as well.

I feel good about being associated with a group that is so aligned with my values and core concerns; I think BCAction is hitting on some of the most important topics in the cancer arena. I’m glad that BCAction is a little “in your face” about it, and a little angry, because I am too. I want to be part of disseminating the great information and messages developed by BCAction, and I also want to have BCAction’s expertise behind me to support me in my own thinking and work.

Generally, I want to use my voice as someone living with metastatic breast cancer to say pharmaceutical cures are not enough. We must focus on prevention. We must address the toxic soup. We must make sure that we reach everyone, so that poverty is not a death sentence.

I want to support people who choose non-toxic treatments. We must give women the freedom to choose less toxic and alternative treatments with the same level of support we give to those who choose the current “standard of care” treatments. I have felt brow-beaten and disrespected by health professionals and many well-meaning others who have discouraged my non-toxic approach to cancer treatment. I don’t disrespect women who choose chemo, why should I be disrespected for not choosing it?

Hydraulic fracturing, or fracking, is one of my key issues and I want people to think before we put those chemicals into the earth to potentially contaminate our water supply. Another of my
issues is local food and I want people to understand the connections between environmental issues and our food supply, what we all can do to help local farmers move from commodity crops to raise food sustainably and humanely, how we all can raise a little of our own food — and why all this stuff matters to our health. I want to raise awareness about what we are doing to the next generation with this huge toxic science experiment we are running.

The cancer system is an enormous money-making machine that is very effective at manipulating public opinion, and I worry that at best they are missing an important part of the point and at worst they are corrupt. I think that a team of smart people who aren’t afraid to buck the norm a little can make a big difference. We can see what is happening to the planet and how it is affecting human health. We must act to protect the next generation. We need to tap the power of educated moms and grandmas to drive change. We need to tap the power of authentic voices based on real experience. I have been reticent to tell my story: who am I to speak up? Will I say the right thing? What if I sound dumb? What if I am criticized? But I am trying to live more fearlessly these days and I’ve decided to dive in, do my best, and hope that the people around me will be there to help me when I need it. My message to people? Join me.

**Education and Advocacy Update: Spring 2013**

**WEBINARS**

Our webinar program seeks to educate members on relevant breast cancer advocacy issues and propose next steps and ways to take action. We continue to engage and educate both new and returning members on various topics including Toxic Cosmetics, Safe Chemicals, Inequities in Breast Cancer, The oversimplification of Screening Mammography, Think Before You Pink® and more. Our webinars are always free and open to the public.

Upcoming webinars will include, The Connection Between Fracking and Breast Cancer on April 29th & 30th and Breast Cancer Media Literacy on May 29th & 30th. Check our website for more information and to view past webinars: www.bcaction.org/webinars.

Here’s what people are saying about BCAction’s webinars:

“Loved loved loved the webinar today. I’m sharing the information with all my friends.”

“I really enjoyed today’s webinar. The content was super straightforward”

“Thank you for a well-organized and presented webinar! I thought the information was very clearly delivered by all the speakers.”
“It was the best webinar I have attended in years! Good speakers and good information.”

“This was well organized. I learned so much, yet I thought I was pretty well informed! Thank you for broadening my horizons.”

“I thought the webinar was well-structured with a good balance between providing information and taking questions. I loved the emphasis on what all of us can do; I loved that it was not just a “this is why you should donate to us” type of talk. Well done, I can’t wait for more!”

SPEAKERS BUREAU
Twenty-three advocates from across the country have joined BCAction’s Speakers Bureau to help change the conversation about breast cancer and identify emerging breast cancer issues in their local communities. Speakers have been hosting events all over the country from house parties to tabling to facilitating small discussions on various breast cancer advocacy topics. For more information about the speakers bureau program and how to apply, contact Sahru Keiser at skeiser@bcaction.org.

Please see this issue’s Member Perspective highlighting current speakers and learn more about why they are passionate about ending the breast cancer epidemic.

FACTSHEETS
BCAction provides concise, science-based information on critical issues to people concerned about breast cancer. We provide a crisp analysis of important breast cancer advocacy topics by challenging assumptions about the disease and inspiring change to address and end the breast cancer epidemic. Each factsheet provides a general overview and framing of the topic, a clear and consistent foundation of information and BCAction’s insight and perspective. We encourage you to share our factsheets with friends, family, co-workers and your larger community. You can find the following factsheets at http://bcaction.org/resources/breast-cancer-action-toolkits/.

- Facts & Myths about Breast Cancer
- The Facts and Nothing But the Facts
- What to Do When Someone You Know Has Been Diagnosed With Breast Cancer
- What You Should Know About Breast Cancer and the Environment
- Ductal Carcinoma in Situ (DCIS)
- En Español:
  - Manual de Informacion y Primeros Pasos para Pacientes con cancer de seno

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El Cáncer de Seno y la Comunidad Latina  
Recetas para la limpiar sin químicos

We love feedback on how our educational materials are useful to you and your community. Send us an email to info@bcaction.org and let us know how you are using our factsheets.

FRACKING
Hydraulic fracturing or “fracking” for short is a destructive method of extracting oil and gas from deep within the earth. Fracking is a growing problem across the country because the process involves polluting groundwater with a cocktail of chemicals, including chemicals linked to causing breast cancer. We are proud to stand up and demand an end to the practice of fracking, and insist that the health of women, and all people, comes before corporate profits. Read more about our anti-fracking work in this issue of The Source.

HUMAN GENE PATENTING AND MYRIAD GENETICS
BCAction is a plaintiff in the case against Myriad Genetics, owner of the current patent on the two human genes BRCA1 and BRCA2 (commonly known as ‘the breast cancer genes’). Myriad’s patent is an obstacle to scientific research on the breast cancer genes and a barrier to progress in research to address the breast cancer epidemic. This case goes before the U.S. Supreme Court on April 15th, and BCAction will be in Washington, DC, rallying to raise visibility for the issue and our work to outlaw gene patenting. We expect a decision from the Supreme Court sometime this summer and encourage everyone to stay tuned. You can read more about the case and our rally at the Supreme Court in this issue of The Source.

Wide Distribution of Think Before You Pink® Toolkit
The Think Before You Pink toolkit provides activists with ways to take action that hold pinkwashers accountable, deepens the understanding of the politics of breast cancer, and pose questions that reveal exactly where valuable pink ribbon dollars go and whether they work to address & end this epidemic. In 2012, we distributed over 10,000 toolkits to activists around the county. Download your copy at http://www.bcaction.org/toolkit.
Special Thanks: Spring 2013

Katie Kanagawa, thank you for your incredible donation of time, talent, dedication, inspiration, and for going way above and beyond!
Miriam Hidalgo, thank you so much for arranging for a great mental health break for staff.
Jason Driskill, thank you for your skill, good humor, and generosity in creating a beautiful logo for our rally at the Supreme Court.
Nneka Leiba, Environmental Working Group, for once again sharing her amazing knowledge and informative presentation on our Nov webinar, Toxic Cosmetics Part 2: Demanding Stronger Regulation
Julie Liou, CA Healthy Nail Salon Collaborative, for her participation and inspiring presentation on our Nov webinar, Toxic Cosmetics Part 2: Demanding Stronger Regulation
H.Gilbert Welch, Dartmouth Institute for Health Policy and Clinical Practice for his engaging and informative presentation on our March webinar, The Oversimplification of Early Detection: Screening Mammography and Breast Cancer Overdiagnosis
Tracy Weitz, Advancing New Standards in Reproductive Health for her clear and concise presentation on our March webinar, “The Oversimplification of Early Detection: Screening Mammography and Breast Cancer Overdiagnosis”
Nancy Schuepbach, for organizing a Pink Ribbons Inc screening in Marin.
Amirah Tyler, National Women’s Health Network for sharing our materials on their table at a number of conferences and outreach events
Sara Brandon, thank you for your steady, dependable presence in the office, helping out with both administrative and development needs.
BCAction Speaker Robyn Stoetzel for organizing the Challenge Breast Cancer Epidemic 2013 event
BCAction Speaker Katherine Shea for representing BCAction at a local health fair and making a presentation at a local university.
JoAnn Loulan, thank you for your powerful, inspiring luncheons that have supported our work for nine years now, and all you do for BCAction.
Yvonne Day for your fabulous ongoing graphic design work — you make us look good!
Louise Epstein, thank you for your insight and support in our year-end fundraising drive.
Kelly Morrell, thank you for helping out in the communications department.
Frances Wall, thanks for helping pack up our supplies for our trip to Washington, D.C.
Seaira O’Brien, thank you for providing staff with a great massage break.
Thank you to Andrea Downing, AnneMarie Ciccarella, Elinor Coleman, Erica Concors, Erika Carlson, Luz Calvo, and Nancy Stordahl for sharing your powerful stories and opinions about Myriad Genetics’ patent on the “breast cancer genes.”
Dorothy Geoghegan and Elaine Costello, thank you for hosting a wonderful lunch get-together with former Board members.

Lee Ann Slinkard, Tracy Weitz, and Ellen Carmody, thank you for your generous donation of airline miles that are getting us to D.C. for our historic gene patent case and rally at the Supreme Court.

Eric Hoffman (Friends of the Earth) thanks for hosting our evening reception on the Myriad gene patent case.

Chris Hansen (ACLU) thanks for coming down to Washington, D.C. from New York to talk with our members about the upcoming Myriad case.

Linda Matt and Erin Caton many thanks for your time and talent in throwing an amazing photo auction event in Apocalyptic Ballerina – A Photo Auction.

Robyn Stoetzel thank you for hosting two workshops to your networks in Illinois; sharing our work and getting folks involved.

Denise Watkins and all participants from Sola Salons, thank you for introducing our work to your community and patrons, as well as fundraising to support our programs.

Karym Uraneta from Pink Horizons thanks for launching a successful campaign supporting BCAction’s work, as well as being a strong business partner.

9th Annual Billie Gardner Loulan Luncheon
Thank you to everyone who made the event such a success!

Event Organizer: JoAnn Loulan
Hosts: Jennifer and Bill Youstra
Invitation and Graphic Design: Amber Raimes – AmberInvited
Guest Speakers:
William H. Goodson III, MD
Stefanie Jeffrey, MD
Event Volunteers:
Jenn Meyer
Amber Raimes
Valerie Russell
Angela Schillace
Donations in Honor and Memory: Spring 2013

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 1, 2012 and April 5, 2013.

20 Year Survivorship
from Jacqueline B. Woody
Gail Barnett
from Brady Den

Peggy Adeboi
from Sheila Gholson
BAYS
from Faith Raider

Veronica Alfano
from Samantha Franklin
Denise Beraud
from Annette Battaglia

All Breast Cancer Survivors
from Sandra and Mel Toponce
Joyce Bichler
from Denise and Todd Helfstein
from Rosey and Stuart Rudnick
from Arlene and Robert Stams

Abigail Arons
from Elissa and Daniel Arons
Sandra Blank
from Bobbi de Cordova-Hanks

Linda Azer
from Nick Azer
Roberta Bonwit
from Joan Finnigan

Jane Balkin Matz
from Simona Angela Ghironda
Eve Borenstein
from Karen Strauss

Phillip Banks
from Phillip Banks
Ruth Borenstein
from Karen Strauss
Diana and Gigi Bowen and Amoguez from Jeff De Loyola

Alison Braverman from Vicki Green

Barbara Brenner from Anonymous (2)
from Joyce Bichler and Michael Kimbarow
from Joan E. Biren
from Joseph S. Brenner
from Claudia Center
from Beth A. Chapman
from Carol Christ and Paul Alpers
from Matthew Coles
from Lillian Sandra Coliver
from Penelope Cooper and Rena Rosenwasser
from Estelle B. Freedman and Susan Krieger
from Judith Gedalia
from Fred Gertler
from Glikman Associates
from Nancy and Alan Goldstein
from Mary Gregory
from Maryann Hickelton
from Joanne K. Hilferty
from Susan Hoffman
from James C. Hormel and Michael P. Nguyen
from Jill C. Israel
from Jill Jakes
from Leonie and Glen Janken
from M. Anne Jennings
from Anne L. Josephson and Dolph J. Vanderpol
from Jane Kahn Michael Bien
from Mary Law
from Rochelle Lefkowitz and Lawrence Kramer

from Elaine Leitner
from Susan Liroff
from Deborah J. Marx
from Marilyn Milkman and Adam Gordon
from Kelly Moran
from Nancy Pemberton and Jeff Parker
from Justin Putney
from Ellen W. Reath
from Ellen Seeherman, Stuart Sloame and Joanna Sloame
from Judith Raphael Shrager and Henry Shrager
from Nina Ginsberg Smith
from Rebecca and Jordan Stanger
from Karen Strauss
from Laurie J. Woodard
from Roberta Gelb
from Barbara Brenner and Susie Lampert
from Irma D. Herrera and Mark D. Levine
from Kyra Subbotin and Henry Siegel
from Ruth Brown
from Laurine Brown
Linda Burnett
from Myra Hindus
from Ivy A. Turner
Jenna Caldwell
from Julie James
from Camp Lejuene Victims
from Samary Seguinot-Medina
Colin Campbell
from Stacey Campbell
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Star Urmston
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Sarah Vradenburg
from Sarah Vradenburg

Michelle Waters
from Robin Keyser

Robin Wear
from Kathleen Clark

Pearl Weiss
from Robert Weiss

Lise Wrigley
from Larry Wartel

Jacqueline Zita
from Karen Clark

Marilyn Zivian
from Frances Singer

Jane Zones
from Anne Salsbury and Jules Steimnitz
from Arlyn Zones and Donald Walker

Dr. Diana Zuckerman
from Edith Mostow
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