



FDA Follows Science in Avastin Decision

By Kimberly Irish, BCA Program Manager

On December 16, the Food and Drug Administration recommended that Avastin (bevacizumab) no longer be used as a treatment for metastatic breast cancer. Like many people, we are disappointed that Avastin never delivered on its promise as an effective treatment for advanced metastatic breast cancer, but Breast Cancer Action agrees with the FDA's decision to follow the science.



In 2007, BCA was the only breast cancer organization to actively oppose Avastin's use for treating patients with metastatic breast cancer. The drug's manufacturer, Genentech/Roche, failed to demonstrate an improvement in overall survival. According to Janet Woodcock, director of the FDA's Center for Drug Evaluation and Research, the phase IV studies showed that patients receiving Avastin did not live longer and, more importantly, experienced a "significant increase" in serious side effects like stroke, heart problems, and gastrointestinal perforation. Avastin's price tag (between \$80 – 100,000 annually) was also a huge concern to BCA and other patient advocates. Last year, Avastin made \$1 billion from its breast cancer indication alone, around a fifth of the drug's total revenue.

To gain FDA approval, BCA believes a drug should do at least one of three things: (1) improve overall survival, (2) improve quality of life, or (3) cost less than therapies already available. Clearly, Avastin did not meet these criteria. In fact, the FDA's chief of cancer drug review, Richard Pazdur, commented, "Given the number of serious and life-threatening side effects, the FDA does not believe there is a favorable risk-to-benefit ratio."

The Source—Winter 2011 | 1.19.11

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In the case of Avastin, the science demonstrates the drug has no overall survival benefits as a treatment for metastatic breast cancer. BCA applauds the FDA for following the science on Avastin and putting the interests of patients before drug profits.

A New Look, Same BCA

By Claudia Cappio, BCA Board President



Change is a constant practice in our lives, and some changes are bigger and therefore more apparent. In recent months at BCA, we've been moving through significant changes. But like everyone, we've risen to meet the challenge and we all remain strongly committed to our core mission and are excited about the opportunities ahead of us.

We are in the process of redesigning our web site. The look is quite different, yet I believe you'll find the content, mission, and action-oriented messages from BCA to be as truth-telling, targeted, and fearless as before. We're working to make the web site easier to navigate, visually more appealing, and functionally more capable. Please stay tuned for the launch.

Of even greater impact is our current search for a new executive director. BCA has been privileged to have had the stability and strength of a visionary executive director who has guided and led the organization for the past 15 years. The board of directors is privileged to be able to build upon such a strong foundation. Even before our new leader is found, BCA board and staff continue to create our future vision. We will continue to build on our priority areas and further engage activists through social networking and new technology. We will continue to collaborate with other organizations, because we know we are strongest when standing together to voice mutual concerns. Yet we remain committed to stand apart whenever necessary to call out an issue that others won't touch.

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Through it all BCA continues to be the watchdog of the breast cancer movement. By not accepting funding from any corporation that profits from cancer or contributes to its cause, we have, and will continue to have, the freedom to tell the truth. We can call out “pinkwashers” such as KFC, join lawsuits against Myriad to say patenting our genes is wrong, and tell Eli Lilly to end the production of rBGH and stop Milking Cancer. BCA’s unique position has always set us apart from other breast cancer organizations.

As 2011 starts, I am reminded of a Quaker adage: “To proceed is to move toward an opening without fear.” We are embracing change and renewing our commitment to BCA’s mission. It’s an exciting balance. I look forward to the year ahead and thank you all for your continued support and involvement with BCA.

Celebrating 20 Years of Kick-Butt Activism

By Belle Shayer, BCA founding member



It’s hard to believe 20 years have passed since we sat around that kitchen table, eight women from a breast cancer support group, determined to do something besides worry. We were determined to make breast cancer a public issue, get Congress to recognize the breast cancer epidemic and provide funds for research, and present facts about breast cancer through a bimonthly newsletter. We turned our frustration into action and thus was born Breast Cancer Action.

I’m proud that over these past 20 years we have been the fearless watchdogs of the breast cancer movement. It hasn’t always been easy, but we’ve stayed in the faces of big pharma, corporations, and the FDA to create positive changes for women living with and at risk for developing breast cancer.

On October 7, 2010, over 300 people came to San Francisco from all over the country to celebrate Breast Cancer Action’s 20th year of [kick-butt activism](#). I was deeply touched to have been honored as BCA’s only living founding mother and to stand

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beside activists [Barbara Ehrenreich](#) and [Rachel Morello-Frosch](#), who were also acknowledged for their invaluable contributions to ending the breast cancer epidemic. We also gave special tribute to my dear friend and lifelong activist [Barbara Brenner](#) for her 15 years of amazing leadership as executive director of Breast Cancer Action.

We must acknowledge that it wasn't just individuals who advanced our work, so we were privileged to honor organizations whose work exemplifies BCA's priorities. [Our Bodies, Ourselves](#) has continued to put patients before corporate profits. [Pesticide Action Network North America](#) is a leader in reducing involuntary exposure to toxins in the environment. [California Latinas for Reproductive Justice](#) works to create better health outcomes for Latina women within a social justice framework. We continue to be inspired by the work of these organizations.

There are so many more activists and organizations to thank, including you. Breast Cancer Action is alive and well because of your commitment to creating a world that is better for each oncoming generation of women. Thank you for [continuing to take action](#) through your support of BCA's work. Together, we will end the breast cancer epidemic.

Breast Cancer Action is deeply grateful to our SPONSORS. Without them, the event wouldn't have happened.

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Breast Cancer Action is grateful to the following people for making the 20th Anniversary Celebration a Smashing Success!

20th Celebration Staff Task Force: Caitlin Carmody, Amy L. Harris, Miriam Hidalgo, Kim Irish, Angela Wall

Art Show and Sales: ArtHaus

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The Source—Winter 2011 | 1.1

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BCA Policy Corner

By Alicia Harris, BCA Program Associate

Recently, Breast Cancer Action increased efforts to exert a positive influence on policy in the Bay Area, the state of California, and the United States at large. As part of our mission to bring about change to end the breast cancer epidemic, we're focusing on policy that will help to create healthy environments by reducing involuntary exposures to toxic chemicals. Members of the BCA staff participated in training and are taking new roles on existing coalitions to increase our capacity for this work.

To enhance my policy work at BCA, this fall I applied to and was accepted by the Women's Policy Institute, a yearlong program sponsored by the Women's Foundation of California. As a member of the Environmental Justice team, I'll work to create a bill and conduct advocacy to pass it through the California legislature. To facilitate this process, I'll participate in four weeklong trainings to build public policy knowledge. Kim Irish, a Women's Policy Institute alumna, is currently participating in a similar program, Reach the Decision Makers, that focuses on policy engagement with the U.S. Environmental Protection Agency. More information is available here:

<http://www.prhe.ucsf.edu/prhe/reachdecisionmakers.html>

On behalf of BCA, Kim joined the steering committee of the California Healthy Nail Salon Collaborative, a coalition of which BCA has been a member for several years. BCA recently testified before the Public Safety Committee of the San Francisco Board of Supervisors to support a local ordinance created by the Nail Salon Collaborative.



The San Francisco Nail Salon Recognition Ordinance, which was passed with a unanimous vote, recognizes salon owners who stop using dibutyl phthalate, formaldehyde, and toluene. These chemicals, commonly found in nail polish, have been linked to cancer, birth defects, respiratory harm, and other health problems. In California, those most exposed to the "toxic trio" are women from Vietnamese

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immigrant communities. We hope that the passage of the San Francisco ordinance will provide a precedent that will positively affect the lives of many women across the United States.

Most recently, BCA has signed on to letters related to a Green Chemistry Initiative in California. This initiative was introduced to identify ways to reduce the impact of toxic chemicals on the environment and human health. Click here for more information: http://www.dtsc.ca.gov/PollutionPrevention/greenChemistryinitiative/upload/California_green_Chemistry_initiative_FAQs.pdf. Despite two years of additional comments from environmental health advocates, the California Department of Toxic Substances Control released a proposal for the initiative that may weaken controls on chemical companies, allowing them to continue manufacturing unsafe products that may endanger our health. BCA signed on to a letter asking California Governor Schwarzenegger to withdraw the flawed proposal. In a huge win, the Department of Toxic Substances Control decided not to move forward with its revisions at the end of December. We'll continue to update members on this legislation and on all our current campaigns via Facebook and Twitter so stay tuned. We've a busy year ahead on the environmental front but it's your active support and involvement that keeps us moving forward.

Highlights from the 2010 San Antonio Breast Cancer Symposium

By BCA Program Manager Kim Irish, and BCA Board Members Jane Zones and Lindsey Collins



This year, three members of the BCA team, program manager Kim Irish and BCA board members Jane Zones and Lindsey Collins, attended the San Antonio Breast Cancer Symposium, the largest annual scientific meeting focused on breast cancer. Following is their report on what they learned.

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Jane Zones:

Before SABCS had its official welcoming Thursday morning, a series of educational meetings for physicians and advocates covered a range of basic topics of interest to women living with breast cancer. The talks on Wednesday, sponsored by the Susan Komen Foundation, were easier to understand and of broader scope than the very focused research reports that began Thursday. I attended talks that focused on genetic testing, radiation techniques, and symptom management.

Sharon Plon, a physician at Baylor University, described family-based genetic sequencing, which identifies the specific mutation or mutations in a person who has breast cancer, so that subsequent testing of a family member who may be at higher risk will hone in on that particular variant. If the cancer patient tests negative, or if variants of uncertain significance (VUS) are found, relatives are not tested. This is a more efficient and less costly way to determine whether relatives have inherited risk than to assess their whole genetic sequence.

The session on managing side effects of breast cancer treatment was moderated by Laura Esserman, a physician at the University of California, San Francisco (UCSF). It included very interesting and potentially useful information on lymphedema, herbal treatments, managing chronic pain, and preventing hair loss during chemotherapy.

Hair loss during chemotherapy is traumatic for many women, and some (as many as 8 percent) avoid it by refusing treatment. Michelle Melisco, a UCSF physician and researcher, reported on "Hair to Stay," a study on the feasibility of chemotherapy patients using a "cold cap" during treatment to preserve their hair. Cooling the scalp to very low temperatures causes vasoconstriction, which reduces biochemical activity and minimizes chemical action on the hair follicles.

Kim Irish:

The conference atmosphere was expectant at the start of the conference as BCA staff, board members, and volunteers planned schedules and set up a table displaying BCA materials in the exhibition hall. Topics covered during the educational sessions

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included advances in neurosurgery related to central nervous system (CNS) metastases and a discussion of the standards for radiation therapy for CNS metastases. The educational sessions were well attended and spurred some interesting questions for audience members to consider.

One fascinating talk, "NeuroSurgical Management of CNS Breast Metastases," was given by Elizabeth B. Claus of Yale University. An estimated 20 percent of breast cancer patients will develop CNS metastases. Risk factors include young age, ER negative breast tumors, and HER2-positive breast cancer. Claus argued in favor of neurosurgery for patients with CNS metastases for several reasons, including relief of symptoms and improvement in quality of life. She concluded that in the appropriate setting, surgery can be a valuable treatment for CNS metastases but that breast cancer-specific trials and data are needed for neurosurgery.

The next session was titled "Radiation Therapy for CNS Metastases: What Should the Standard Be?" given by Minesh P. Mehta, a physician at Northwestern University. Mehta is a consultant for a huge array of pharmaceutical companies — Adnexus, Bayer, Merck, Schering, Genentech, and Tomotherapy. Mehta recommends that surgical resection followed by whole brain radiation therapy (WBRT) is a better treatment option for improving tumor control at the original site of the metastasis and in the brain overall when compared to surgical resection alone. Stereotactic radiosurgery (SRS) alone may provide an equivalent survival advantage for patients with brain metastases compared with SRS combined with WBRT.

From a patient perspective, some important questions were raised during the presentation titled "Systemic Therapy for CNS Metastases," by Nancy U. Lin, a physician at the Dana-Farber Cancer Institute. Lin noted that FDA-approved drugs are currently not available for systemic treatment of brain metastases. Her presentation discussed the many unresolved issues related to systemic therapy, including determining the meaningful endpoints and how should they be defined, how much data is required before doing a trial in untreated patients, and what is the appropriate follow-up for treated patients. Lin concluded with the observation that systemic therapy for CNS disease is an area of increasing research interest, so more data may be forthcoming.

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Lindsey Collins:

While sitting in Friday morning's panel, BCA's executive director, Barbara Brenner, forwarded us a press release from Genentech on NEOSPHERE, its phase II trial on the combined use of Herceptin (trastuzumab) and pertuzumab with chemotherapy for early-stage HER2-positive breast cancers. The press release celebrated the results and cited the presentation at San Antonio. Not quite — the Genentech/Roche people hadn't presented yet. Neil Spector, a physician from Duke University, was still talking about therapies that target HER2-positive breast cancers and the problem of women developing resistance to HER2 drugs such as trastuzumab. Spector suggested that adding lapatinib (Tykerb) and pertuzumab to Herceptin could have good effects even after women become Herceptin resistant, which often happens after 12 months. If women become resistant to trastuzumab (Herceptin), he asked, how can we block HER2 and make it affordable and accessible to women? To paraphrase, Spector asked, "If only four women can afford this therapy, then we have to ask what the hell we're doing." What the hell, indeed. Herceptin can cost patients anywhere between \$42,000 and \$65,000 a year.

That was an interesting transition into Luca Gianni's presentation for Genentech. Gianni, the director of medical oncology at the National Cancer Institute in Milan, Italy, and principal investigator for the NEOSPHERE trial, neglected to mention the cost of a combined trastuzumab and pertuzumab therapy, which could easily top \$100,000 a year (given that Herceptin alone can cost that much). The study recommends that the trial proceed to phase III due to findings in animal models that pertuzumab enhances the antitumor activity of trastuzumab in early inflammatory, locally advanced, or HER2-positive cancer. The study's endpoint is pathological complete response (pCR), or complete tumor disappearance at the time of surgery, and found that the addition of pertuzumab and docetaxel (chemotherapy) achieved a pCR rate of 45.8 percent. The pCR for just Herceptin (trastuzumab) and pertuzumab was 16.8 percent. The study asserted that "a proportion" of HER2-positive tumors can be eradicated without chemotherapy with the trastuzumab-pertuzumab therapy. The study also found that there is no added toxicity and that "tolerability is good" for this combination. In other words, you'll still probably have a reduced white blood cell count, diarrhea, and some frightening heart problems, but not a whole lot more. It's important to also note that

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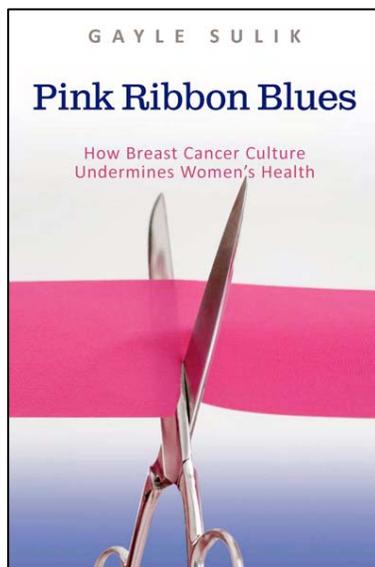
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the study didn't look at long-term outcomes, only tumor reduction until the time of surgery. There's no data on whether this therapy works 12 months after surgery and beyond. The press release identifies side effects for Herceptin, which include diarrhea, fever, vomiting, heart problems, reduced blood cell counts, and infusion reactions, but neglects to elaborate on side effects of the Herceptin-pertuzumab combination or this combination and chemotherapy, other than the brief explanation in Gianni's presentation about "no significant additional toxicity." Unfortunately, lack of detail doesn't mean lack of side effects.

Book excerpt: *Pink Ribbon Blues* by Gayle Sulik (Oxford University Press, 2010)

Compiled by Caitlin Chappelle, BCA Communications Associate

The following two excerpts are from Gayle Sulik's recently released book, [*Pink Ribbon Blues*](#). Breast cancer is spoken about more than most other diseases. Yet increased dialogue has not come without a price of unfortunately superficial terms: "I <3 boobies," "Save the ta-ta's," "Beat the hell out of breast cancer," to name a few. Many readers will be familiar with the stories Sulik cites. Her book is provocative and



we encourage anyone who is interested to take a look at it and consider the costs and benefits of increased "awareness" and the incredible amount of action still needed to end this epidemic.

In the first chapter of *The Cancer Journals*, "the transformation of silence into language and action," Lorde emphasizes the importance of illness narratives. Putting what she feels into words enables the ill person to reflect on her experience, examine it, put it into a perspective, share it, and make use of it. Lorde argues forcefully that communicating our experiences not only benefits the speaker on a personal level, but also gives voice to realities that will cause harm if left unattended. She writes:

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I was going to die, if not sooner then later, whether or not I had ever spoken myself. My silences had not protected me. Your silence will not protect you...while we wait in silence for that final luxury of fearlessness, the weight of that silence will choke us.

For Lorde, it is the truthful telling of all kinds of stories that matters, not only those accepted in the broader culture. Her goal is not to construct a singular Truth, such as the story of the triumphant survivor, but to create opportunities for women to seek out and examine a diversity of stories and consider their relevance to their lives...

In the early 1990s... breast cancer activism was starting to gain momentum in extending public outreach, increasing research funding, and gaining a seat at the public policy table. In August 1993, *The New York Times Magazine* published a story about the achievements of the breast cancer movement with the title "[You Can't Look Away Anymore.](#)" The caption referred both to the success of the movement in agitating for change and to the photograph on the cover.

"Beauty Out of Damage" is a graphic self-portrait in which the artist and activist, [Matuschka](#), bared her mastectomy scar. Unlike typical images of breast cancer survivors, the explicit nature of the photograph sparked significant controversy about how breast cancer should be presented to the public.

Matuschka's now-infamous photograph has appeared in hundreds of international publications, books, television shows, and documentaries. Some of the commentary about the photograph accused her of exploitation, but Matuschka told interviewers that her photographs were not created with the expectation of financial gain. So, why did she do it? The artist says why in a response in *Glamour Magazine* later that year:

I have always adhered to the philosophy that one should speak and show the truth, because knowledge leads to free will, to choice. If we keep quiet about what cancer does to women's bodies, if we refuse to accept women's bodies in whatever condition they are in, we are doing a disservice to womankind.

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Since its cover debut, “Beauty Out of Damage” received 12 awards, including a Pulitzer Prize nomination. The silence that once surrounded breast cancer had been broken. Fifteen years after the Times Magazine confronted the “anguished politics” of breast cancer, representations of breast cancer are everywhere. Pink ribbons and talk of breast cancer awareness in everyday social spaces must mean that, unlike the dark and quiet past, we now have an exhaustive number of ways to show and speak the truth about breast cancer.

Regrettably, women and their support networks are now hidden beneath a barrage of pink ribbons and silenced in a cacophony of pink talk. The accepted discourse of pink ribbon culture—solidly lodged in war metaphor, triumphant survivorship, pink consumption, and narratives of quest and transcendence—limits the words, plotlines, and imagery available to communicate women’s varied experiences of breast cancer and ways of coping.

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Susan M. Cohen, Lifetime activist and BCA supporter, Remembered

Breast Cancer Action is deeply saddened by the news of the death of our longtime friend, supporter, and fellow activist Susan M. Cohen, 69, who died on December 22, 2010 in New York City. Susan was Manhattan Legal Services Senior Staff Attorney and Community Justice Project Coordinator. She dedicated her life to helping those who needed support and self-empowerment. Her work with poor and disadvantaged communities extended from housing justice into healthcare inequalities. Her passion for political and legislative advocacy as a means to achieve change was an inspiration to us all. Diagnosed with breast cancer over 16 years ago, Susan was chair of the New York State Breast Cancer Network. The organization, which she co-founded in 1998, is composed of 25 groups throughout New York State with a focus on grassroots, survivor-driven support and education services for women with breast cancer. In lieu of flowers, donations are being directed to Breast Cancer Action (www.bcaction.org), SHARE (www.sharecancersupport.org), or Vassar College (Poughkeepsie, NY).

The Source—Winter 2011 | 1.1

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ISSN #1993-2408, published quarterly by BCA.

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BCA gratefully acknowledges donations made in honor of the following individuals between September 17, 2010 and December 15, 2010.

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DONATIONS IN MEMORY

BCA gratefully acknowledges donations made in memory of the following individuals between September 17, 2010 and December 15, 2010.

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Gratitudes

Fotowatio Renewable Ventures, Inc., for a very generous in-kind donation of laptop computers.

Alan Kleinschmidt and the SF Choral Society, for complimentary tickets for our staff, volunteers, and board.

Caren Cummins, for her over-the-top office assistance.

Carol Fong, for coming back to help in the office!

Art Zigas, for a generous in-kind donation of office furniture.

Gayle Sulik, for allowing BCA to print an excerpt from *Pink Ribbon Blues*.

All the bloggers, journalists, and BCA members who drove the pink conversation to real issues during the most recent Breast Cancer Industry Month.

Linda Thai, for her continued office support and willingness to go the extra mile not once but twice a week.

Jane Zones, Tori, Zoe, and Sasha Freeman, for bringing holiday cheer to the office with yummy goodies.

Mary McCann, for leading a lunchtime fundraiser at her workplace and choosing BCA as the beneficiary.

Suki, for choosing BCA as the beneficiary of 100 percent of proceeds from the sale of its [exfoliate foaming body](#) cream during the month of October.

Paula Siddens, for hosting a holiday party and choosing BCA as the beneficiary.

Catherine DeLorey, for directing donations to BCA in lieu of birthday gifts.

RunwayJunkie.com, for featuring BCA on its home page!

Landor, for choosing BCA as the beneficiary of its Pink Week events.

Miriam Hidalgo, for her amazing work revising BCA's factsheets!

BCA board members **Jane Zones and Lindsey Collins**, for attending the San Antonio Breast Cancer Symposium; and volunteers **Carmelita Austin-Schreher, Joan Kelley, and Krisanne Salquest**, for their help staffing the BCA table there.

Marc and Karen Irish, for donating computer equipment.

Anita Bowen, for donating her fabulous photography talents.

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