



From the Executive Director: Resist, Resist Resist!

By Karuna Jaggar, Executive Director

Since our founding, Breast Cancer Action has been a small organization with an outsized impact. We do this by always asking ourselves: how can we use our organizational skills and resources most effectively in demanding health justice for women affected by breast cancer, and supporting a broader progressive movement for social justice?



This question looms larger than ever after the 2016 election radically altered our national political landscape. There's so much at stake right now when it comes to healthcare access, cancer research, and public health protections like toxic chemical regulations.

So what's ahead in our work for health justice in this new political climate?

The current administration is seeking to repeal and/or weaken the Affordable Care Act (ACA), which is an imperfect but critical piece of legislation that helped millions of people, including women with breast cancer, access healthcare. We are working not only to defend the gains made under the ACA but also to improve health coverage and have put forward a vision for universal healthcare. In this issue, you'll read about the defeat of legislation that would have repealed the Affordable Care Act and stripped healthcare from 24 million people. And don't miss member Wendi Dennis' story about needing access to healthcare as a breast cancer patient.

We have a unique (and unfortunately rare) role as a patient advocacy group that doesn't take pharma funding, so we'll be doing more to help bring down the unconscionably high cost of cancer drugs, while continuing to demand drugs are safe and effective before the Food & Drug Administration approves them. Stay tuned for an action alert about opposing Trump's nominee to head the FDA, Scott Gottlieb, who would be the most interest-conflicted commissioner in American history.

On the flip side, some of our work in the coming months and years will be more defensive than usual. For example, the past few years we've been pushing the Environmental Protection Agency (EPA) and Food and Drug Administration (FDA) to do more to protect us from toxic chemicals linked to breast cancer; now we'll also be working to ensure we don't lose basic protections already in place, especially since the new EPA administrator, Scott Pruitt, is notoriously hostile to the agency's core mission of protecting human health and the environment.

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We are in this for the long haul. We know we can't end the breast cancer epidemic without demanding fundamental changes in our profit-driven society. And we refuse to start thinking small now. We may "lose" more in the short term, but we always have our eye on building momentum for needed systemic changes. Last month, we asked you to oppose the nominations of Scott Pruitt and Tom Price to President Trump's cabinet, and you did, along with thousands of people across the country. Even though the Senate confirmed them both, our resistance was far from fruitless. Our ongoing resistance builds our collective power to demand quality healthcare and protection from toxic chemicals, and to put this administration on notice that we will not stand silently by as they harm women's health.

There are some things that won't ever change about our work. We will always be a fiercely independent voice for women's health. We will always refuse corporate funding from any company that profits from or contributes to the breast cancer epidemic. We will always get to the roots of the breast cancer epidemic and demand true system changes that will benefit all our health.

We need your support now more than ever. As we face the difficult year(s) ahead, now's the time to step up your support to Breast Cancer Action and join our circle of monthly donors. Your monthly donation to Breast Cancer Action is an investment in social change, and an important form of grassroots activism.

Thank you for standing up and resisting threats to our health.

Disastrous "Healthcare" Bill Went Down in Flames, Thanks to You

Disastrous legislation that would have stripped healthcare from millions of people went down in flames, thanks to you and hundreds of thousands of people across the country who stood up to defend our healthcare.

Together we resisted and said "hell no" to taking away healthcare from millions of people who are already the most vulnerable: poor people, people of color, women, people with chronic health problems, and older people—all to give huge tax breaks to the wealthiest people in the country.



We are deeply relieved. And we are profoundly grateful for all the ways you joined us in standing up for the healthcare needs of everyone in the U.S. Access to affordable healthcare is life or death for women at risk of and living with breast cancer.

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Make no mistake, there are very real problems in our healthcare system, even after the gains of the Affordable Care Act. 28 million people still do not have health coverage, and healthcare costs are still dangerously high. But this “healthcare” plan was not the answer to any of these problems, and we are relieved to see its demise. What we truly need is a healthcare system that guarantees affordable, high-quality healthcare to everyone.

Notably absent from the public fight to save healthcare for millions of women were many of the major breast cancer organizations who raise hundreds of millions of dollars each year in the name of women with breast cancer. This is shameful. That’s why our small and mighty team needs your help more than ever. Can you help fund the ongoing fight for health justice for all women at risk of and living with breast cancer by signing up for a monthly donation today? Your support makes it possible for us to take on critical issues like this. <http://www.bcaction.org/monthlydonor>.

Thank you so much for standing up for healthcare for all.

P.S. If you haven’t already, be sure to read blogger Wendi Dennis’ story about how the Affordable Care Act helped her access healthcare, and why we need universal healthcare. You can read it on our blog at <http://www.bcaction.org/blog>.

Demand Equal Access to Lymphedema Treatment

By Leslie Riddle, Program Officer

Our friends at the Lymphedema Advocacy Group recently lobbied Congress in Washington, D.C. for better coverage of lymphedema treatment. Even though the attempt to repeal the Affordable Care Act failed, we still need to fix a critical gap in insurance coverage for lymphedema treatment. Ask your members of Congress to cosponsor the Lymphedema Treatment Act at <http://www.bcaction.org/take-action>.



When lymph nodes are removed or damaged during breast cancer treatment, it can result in painful and debilitating swelling. This condition is known as lymphedema and experts estimate that from 20% to 30% of women will experience some level of lymphedema after breast cancer surgery or radiation.

Currently, Medicare and many private insurance policies fail to cover the costs of the daily compression supplies people with lymphedema need to control their swelling. People who can’t afford these supplies are left with worsening lymphedema, which can lead to infections and even long-term disability.

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The Lymphedema Treatment Act would end this injustice by changing Medicare law to cover compression supplies—setting an important precedent for Medicaid and other insurers to do the same.

Right now is a key time to ask your legislators to cosponsor the Lymphedema Treatment Act. Last Congress, the bill had 290 bipartisan cosponsors and you can help regain that support and get the bill passed this year.

All women deserve access to comprehensive lymphedema treatment. Make sure your legislators know you care about access to lymphedema treatment and you want them to fight for it.

Rare Blood Cancer Linked to Breast Implants

By Karuna Jaggur, Executive Director

In 2011, the Food and Drug Administration (FDA) identified a possible association between breast implants and the development of anaplastic large cell lymphoma (ALCL), a rare type of non-Hodgkin's T-cell lymphoma. Last week, the FDA published a new statement about this association, reporting that out of 359 reported cases of ALCL following breast implants, nine women have died. New research over the past six years (since the FDA first acknowledged a "possible link") has prompted the FDA to report an established association, saying that "women with breast implants have a very low but increased risk of developing ALCL compared to women who do not have breast implants."

The FDA's updated statement last week brings the agency's position into alignment with the World Health Organization (WHO) which has acknowledged the association between ALCL and breast implants since 2016. Although rare, cases of ALCL associated with breast implants, like other serious complications from medical devices, are under-reported to the FDA. There is not currently enough data to conclude how common breast implant associated ALCL is in the U.S.

Most of the time, treatment of ALCL involves removing the implant, but can also include chemotherapy and radiation if there is lymph node involvement or broader spread of the disease in someone's body.

Breast implants can be used in reconstruction after breast cancer and, more frequently, for breast enlargement as an elective cosmetic procedure. The New York Times reports that of the 400,000 women in the U.S. who received implants in 2016, 109,000 were for reconstruction after breast cancer.

Onset of this rare type of lymphoma can develop many years after the implant. The WHO reports that the median interval from the time of the implant to the development of lymphoma is 10 years.

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Although cases of ALCL have been associated with both smooth and textured breast implants, the vast majority (nearly 90%) of the reported cases where the texture of the implant is known occurred with textured implants. Textured implants have been used since 1990 to prevent rotation for newer “anatomically shaped” implants and also to help prevent capsular contracture, which is a complication from surgery where scar tissue around the implant becomes hard and painful.

My commitment to ensuring that women have access to unbiased, comprehensive, and evidence-based information as they make decisions about breast care is what brought me to Breast Cancer Action. Too often, women are given medical information only in very broad strokes when they are diagnosed with breast cancer, and many come to find after making treatment decision that they weren't informed about all of the potential side effects. Every patient deserves the time and information to understand the full range of their options and make the decision that is right for them, which may be different from someone else's decision in the exact same circumstances.

Many women who elect to undergo breast reconstruction later report receiving less than complete information about breast implants in their medical consultations about the procedure. For example, many women who experience complications later say they are surprised to learn that between a quarter to a third of implants require a second unplanned surgery—with some studies reporting complications for nearly half of implant surgeries. They also often learn from other women, rather than their healthcare team beforehand, that there can be pain, burning, and itching sensations. They are told that the implant will “look and feel” normal, not that their chest will be numb after a mastectomy or that the implant will always feel cold. They are told that implants are safe, but not about a rare blood cancer or other serious health risks associated with implants.

Every medical procedure comes with risks and benefits and breast implants are no different. However, too often surgeons gloss over the rare risks and serious harms of implants. I've heard surgeons at countless breast cancer conferences bemoan the low rates of reconstruction, particularly for women of color, and wonder how to encourage more women to opt for reconstruction, without acknowledging the risks and harms associated with the procedure.

Rather than simply reassuring women that breast implants are safe and have good cosmetic outcomes, surgeons should support informed decision-making by discussing the full range of side effects with their patients, including the rare risk of anaplastic large cell lymphoma (ALCL), which have been associated with implants. Women are fully capable of assessing risks and benefits and making the treatment decisions that are right for them.

The twenty-year history of concerns about breast implants is a cautionary tale at a time when the Trump administration considers vast budget cuts to the FDA and has nominated an FDA Commissioner who is decidedly pro-industry and may weaken safety standards. We cannot afford to let rare side effects go unreported and understudied—and leave women uninformed.

Every woman deserves to make her own informed decision, weighing the risks and benefits based on her values and priorities. The burden is on our public health systems, regulatory agencies, and

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health providers to support each woman in truly informed, evidence-based, individual decision-making.

Why We Oppose Scott Gottlieb to Head the FDA



President Trump has nominated Scott Gottlieb as the next Commissioner of the U.S. Food & Drug Administration (FDA). We strongly oppose Gottlieb's nomination and sent the letter below to The Honorable Lamar Alexander, Chairman of the Committee on Health, Education, Labor & Pensions.

Dear Mr. Chairman,

Breast Cancer Action is strongly opposed to the nomination of Scott Gottlieb as the next Commissioner of the U.S. Food and Drug Administration (FDA). Our opposition stems from concerns regarding Dr. Gottlieb's strong industry ties and resulting conflict of interest, as well as his views on loosening FDA regulations that threaten to undermine patient protection.

Breast Cancer Action (BCAction) is a national education and activist organization working to achieve health justice for all women at risk of and living with breast cancer. Since our founding 27 years ago, we work to ensure that women have access to evidence-based information about breast cancer, free of industry influence. BCAction has over 60,000 members across the U.S.

We have deep concerns about Dr. Gottlieb's strong ties to the pharmaceutical and biotechnology industries. He serves as a consultant or advisor to companies such as Gradalis, Glytec, Tolero Pharmaceuticals, GlaxoSmithKline, and Vertex Pharmaceuticals. According to ProPublica, he received more than \$400,000 in payments from pharmaceutical companies between 2013 and 2015, and Harvard University's Dr. Daniel Carpenter, who wrote a history of the FDA, stated that if confirmed, Gottlieb would be "the most interest-conflicted commissioner in American history." We cannot trust someone so deeply connected to industry to be able to put patient interests first and foremost. In addition, his industry ties resulted in his recusal from many key decisions during his previous tenures with the FDA, which gives us great concern were he to serve as FDA Commissioner.

We are specifically concerned that Dr. Gottlieb has been a long-time advocate for loosening approval requirements for new medical products; speeding the process for approving complex generics; and increasing flexibility in the clinical trial process. The FDA already approves new drugs

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faster than any other developed country. And the agency is currently on the path to even speedier drug approvals; the recently passed 21st Century Cures legislation is a prime example. We are gravely concerned that Dr. Gottlieb's appointment will focus on accelerating this process at the expense of safety and efficacy standards. Rather than benefitting patients, there is a very real risk that shortchanging the approval process may result in a greater risk of side effects or, worse, lethality with no guarantee of efficacy.

We are additionally opposed to Dr. Gottlieb's nomination given his criticism of government restrictions on how companies could market drugs for off-label uses. We need an FDA Commissioner who will uphold the agency's role of ensuring that clinical decision-making is informed by strong clinical evidence on a drug's intended use.

Patients and consumers depend on the FDA to protect the public's health and safety. We believe that an FDA Commissioner with such strong industry ties and a history of criticizing regulation is not the right candidate. On behalf of all women at risk of and living with breast cancer, we urge you to reject Dr. Scott Gottlieb's nomination.

Sincerely,

Karuna Jaggar
Executive Director, Breast Cancer Action

Special Thanks

We could not do this work without the support of so many members and volunteers.

- Thank you to Jeremy and Erika Carlson for going above and beyond to ensure our new brochure conveys who we are and what we do!
- Thank you to Dr. Shelley Hwang for sharing her time and expertise on our webinar, "Is the 'C' in DCIS Really Cancer?"
- Thank you to current and former Board members Abigail Arons and Lori Baralt for offering their insights on our webinar, "Grassroots Fundraising With Integrity."
- Thank you to Briann DeOrnellas for your weekly volunteer support.
- Thank you to Amy Tom for all your help with mailings in the office.
- Thank you to Virginia Price for hosting a wonderful benefit for Breast Cancer Action in your beautiful home.



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- Thank you to Alan Kleinschmidt and the SF Choral Society for the generous offering of tickets to their phenomenal performances for our staff, board and volunteers.
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- Thank you to Janna Bey who showed up from start to finish when we were in a real pinch to get a time sensitive mailing out.

Thank you so much to everyone who helped make our 5th annual Acting Out – For the Health of It variety show such a success!

Performers

- Tania Katan, emcee
- Alexandra Fraser
- Nazelah Jamison
- Jo Kreiter and Vitali Kononov
- Thao Nguyen
- Yamini Kesevan Ranchod
- Rusty Stringfield
- "Misisipi" Mike Wolf

Event Sponsors

- Kazan McClain Partners' Foundation
- Mechanics Bank
- Pratap and Chitra Pal
- Susan Wood

Event Committee

- Abigail Arons
- Julie Morgan

In Kind Donors

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- Buena Lane Photography
- Dandelion Chocolate
- Delfina Restaurant Group
- El Charro
- Giggling Lotus
- Coffee Shop
- Hattie Dague Bodywork
- Heather Haxo Phillips Household
- Hi-Lo
- The Hideout Kitchen & Café
- Kiss My Ring
- La Palma Mexicatessan
- La Piazza Pizzeria
- Lily Spruce
- Noe Valley Bakery
- Nourish
- Nuri's Kitchen
- Catherine and Jonathan Ogle
- Olive This Olive That
- Phoenix Salon and Day Spa
- Pier 39
- Planet Granite
- Pressed Juicery Household
- Virginia Leung Price
- ReLove
- Ritual Coffee Roasters
- San Francisco Symphony
- Sanvitalie
- Shotgun Players
- Swad Indian Cuisine
- The New Parkway Movie Theater
- Tingzin Ellis Pilates
- Vanessa Verlee Household
- Waterbar
- Yoga Tree
- Alamo Draft House
- Orange Kettlebell Club
- Ryan Rockland

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Donations in Honor and Memory

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

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

Donations Made in Honor

BCAction gratefully acknowledges donations made in honor of the following individuals between November 15, 2016 – March 30, 2017.

Abigail Arons
from Elissa Arons
from Joy Riskin
from Wendy and Jim Mnookin

Abigail Arons and Matthew Bennett
from Lily Dorment
from Joanna Pozen
from Melissa Robin and Michael Caplan

Alison Braverman
from Vicki Green and Robert Curry

Alison Jaggar
from Sumita Jaggar and Tim Dubbs

All of those who have suffered
from Ron and Sydney Crawford

All Oncology Nurses
from Dianne Romanos

Ariadne Pascual
from Maria Rogers-Pascual

Audrey Dunaway
from Teddy and Franklyn Harrison

Babs Attard
from Ms. Barbara Attard

Barbara Brenner
from Shelley Alpern and Marjorie Kelly
from Cathy R. Fischer
from Cari Napoles
from Ellen Seeherman and Stuart Sloame
from Allison Wolpoff

Barbara Carberry
from Susan Pelletier

BAYS
from Emily Kaplan

BCAction board and staff
from Marie Bautista

BCAction Staff
from Joyce Bichler and Dr. Michael Kimbarow
from Karuna Jaggar and Dave Otten

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Belle Shayer
from Reva and John Segall

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from Joseph S. Conway

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from Denise Notzon

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from Annette Silver

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Carol Copsey
from Helen Fitzsimmons and Laura Mamo

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Association

Catherine Silverman
from Lisa Decker

Elizabeth Seja Min
from Judith Patrick

Cindy Beck
from Jennie Skancke

Ellen Schwerin
from Lee Sider

Deborah Mendelsohn
from Carole L. Mendelsohn

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from Jess Weida

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Gaye Doner Tudanger
from Joy Doner-Mazzeo

JoAnna Granovetter
from David Granovetter

Gayle Goldman
from Jessica and Benjamin Rosenberg

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from Jocie, Jerome and Jan Sobieraj

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from Bella August

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from Martha Ham
from Michelle Mercer and Bruce Golden
from Doug Paxton
from Danielle Silver

Karen Klein and Ben Golvin
from Eve Meyer

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from Adrienne Torf
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Madeline Kanner
from Dr. Margaret Rose Draeger
from Margaret Holde
from Rosalie Hewins

Margot Friedman
from Ms. Amy Cotton

Mary Elizabeth Johnson
from Dennis Fong

Me!
from Laura Smith

Melissa Peacock
from Devon Webster

Mom, Beth, Rachel, Hope, Stephanie, Stacey,
and more
from Dena Taylor

My Brilliant Coworkers
from Zoe Christopher

My dear wife Pearl
from Robert Weiss

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My Mom
from Lisa Bedard

Ruth Borenstein
from Karen Strauss

My sister, Marybeth Gallagher
from Barbara Maher

Salom Williams
from Trey Williams

Nancy Grail
from Carolyn Nelka

Sarah Douglas
from Karen Steinbach

Nancy Klein
from Kendra Klein

Sister, Sue
from Ms. Mary Enright-Olson

Ngina Lythcott
from Eileen Counihan

Sue Sawtelle
from Ms. Jennell Parr

Pamela Altmeyer Alvey
from Terri Morris Downs

Susan Tygel
from Ellen Sue Spicer-Jacobson

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from Martha Crusius and Tom Lent

Susana
from Joanna Uribe and Manuel Mena

Patty Doyle and Barb Doyle
from Sandra Schultz

Susie Lampert
from Karen Getman
from Michael Rice

Paula Gordon
from Diane Neary

Tania Katan
from Jennifer Duncan

Peg and Karen
from Arthur Stevenson
from Rev Janice Fairchild
from David Fairchild

The all powerful ME. I will never again choose
an asskicker lesson like that again. Love to
THE amazing BCA
from Deborah Servetnick

Roberta Bonwit
from Joan Finnigan and Mark Matteucci

The Athey Grandchildren
from Coral J. Fry

Rochelle Wunsch
from Barbara Wunsch

The Oncology Support Program
from Barbara Sarah

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Tina Barnes
from Betsy Aubrey and Steve Lichtenberg

Anonymous
from Melissa Robin and Michael Caplan

Yamini Kesavan
from Sanjay Ranchod

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Asmita Saoji
from Mayuresh Saoji

Alison McCreery
from Laurie Pomeranz

Babs Attard
from Ms. Barbara Attard

Alma Warner (Grandmother)
from Kathryn Davis

Barbara Brenner
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