Engaging
COMMUNITY

Expediting
RESEARCH

Eliminating
BREAST CANCER

IN MARIN COUNTY
AND BEYOND

zero
breast cancer®
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LETTER FROM THE DIRECTOR

When breast cancer survivor Francine Levien formed Marin Breast Cancer Watch in 1995, Marin County residents were alarmed, scared, and ready to organize. Marin County’s breast cancer rates were higher than anywhere else in the world, and the question that virtually everyone asked, and no one could answer, was, why?

Researchers still cannot fully answer that puzzling question. In part, this is because the answers are far more complex than the small group of breast cancer survivors who established the group, now called Zero Breast Cancer, initially believed. This is also why our quest to uncover the reason for Marin’s high breast cancer rates has taken us beyond our county’s borders to become a respected leader, both locally and nationally, advocating for and educating the public about research on breast cancer and the environment.

Three overarching principles have guided our work: engaging community, expediting research, and eliminating breast cancer. Following these ideals, we have collaborated with researchers to design studies that address our community’s specific concerns. We have advocated for more research focused on the environment and breast cancer. And we have provided our community with clear, relevant, and reliable findings from breast cancer research that they can use day-to-day and that can inform public policy decisions that ultimately will prevent breast cancer.

From the outset, we have differentiated ourselves from other breast cancer organizations through our unique involvement in research, which continues to be a hallmark of our work. This report details what we have accomplished, what we have learned, and how we have applied what we have learned to our primary purpose: preventing breast cancer.

Our achievements would not have been possible without the support and involvement of the incredible women and men in Marin County and throughout the San Francisco Bay Area who have worked with us, donated to us, and supported our efforts in myriad ways. What we have accomplished in the Bay Area serves as a model for other communities interested in addressing environmental and public health concerns.

I encourage you to sign up on our website, www.zerobreastcancer.org, for our email alerts and newsletter, which will keep you informed about our work and the latest research on breast cancer and the environment. We remain committed to uncovering the reasons why breast cancer rates remain high in Marin County and the San Francisco Bay Area, and to finding the answers that will help end this disease everywhere.

Breast cancer is a disease that affects all of us—our families, friends, coworkers, and community. In turn, it will take all of us to make “zero breast cancer” a reality for the next generation. We look forward to achieving this goal with you.

Janice Barlow
Executive Director
Zero Breast Cancer
We’re moving to paradise,” I announced 12 years ago. when my husband and I bought a house in Marin County, just north of San Francisco’s Golden Gate Bridge. Famed for its mellow lifestyle, towering redwoods and rugged coastline, Marin—one of the most affluent counties in the nation—seemed picture-perfect, a place anyone would want to live.

For many years, as I roamed Marin, the scene never failed to offer a sense of peace and tranquility. The county’s natural beauty, coupled with its laid-back lifestyle, made it a haven for those seeking a break from the hustle and bustle of the city. But as I’ve been here longer, I’ve noticed a change. A change that has left me wondering if the paradise I once knew is really the paradise I’m living in today.

The Canaries of Marin County

by Dianne Hales

The study of Bay Area girls has identified higher health risks for children in Marin County.

October 2002

Breast cancer probe voted

National health agencies join to study Marin’s high rates

Wednesday

What’s KILLING the WOMEN of MARIN COUNTY?

This suburban utopia has presidential visits, a health-conscious, typically fit population—and perhaps the highest breast cancer rate in the country. What’s going on? Ginny Graves investigates

October 2002

Health

The New Breast Cancer

Hot Zone

Stricken with the country’s highest rate of breast cancer, the women of Marin County, California, are asking hard questions about toxins in the environment. What are they learning may change your life.

October 2002

Marin Independent Journal

Marin Independent Journal

November 2000

Review of Marin’s high rates of breast cancer

October 2002

Marin Independent Journal

Marin Independent Journal

November 2000

City of Marin’s high rates of breast cancer

October 2002

Marin Independent Journal

The new breast cancer hot zone

Stricken with the country’s highest rate of breast cancer, the women of Marin County, California, are asking hard questions about toxins in the environment. What are they learning may change your life.

October 2002

Marin Independent Journal

The new breast cancer hot zone

Stricken with the country’s highest rate of breast cancer, the women of Marin County, California, are asking hard questions about toxins in the environment. What are they learning may change your life.
In the early 1990s, researchers began to report a series of troubling statistics about breast cancer in Marin County and the wider San Francisco Bay Area. The problem the community faced was outlined clearly in 1994 in the Northern California Cancer Center’s report *Breast Cancer in the Greater Bay Area*:

- White women in the San Francisco Bay Area had the highest recorded rates of invasive breast cancer in the world.
- African-American women in the San Francisco Bay Area had the fourth-highest incidence of breast cancer of any group of women in the world.
- Marin County had the highest breast cancer rate in the Bay Area.

When the report was released, the San Francisco Bay Area breast cancer advocacy movement was only in its infancy, but it didn’t take long for Marin County breast cancer survivor Francine Levien to bring together an amazing group of women around her kitchen table who were ready to take action. They named their fledgling group Marin Breast Cancer Watch (MBCW), and they set out to educate themselves and others about what was happening in Marin. Their activism quickly garnered widespread media attention, in part because the situation was so incongruous: How could Marin County, known for its natural beauty, healthy lifestyles, and relative affluence, be, as one media outlet put it, “the breast cancer capital of the world”?

The breast cancer advocates who founded MBCW didn’t just want to ask questions and wait for answers. They wanted to actively collaborate with scientists and conduct breast cancer research that would help them determine what was in their personal and physical environment—Was it the air? The soil? The products or medications they used?—that contributed to the breast cancer epidemic in their community.

**OUR PURPOSE**

The primary purpose of Zero Breast Cancer is to prevent breast cancer. We collaborate with local and national scientists on studies designed to identify the causes of breast cancer and breast cancer recurrence. Our efforts are focused on communicating science-based findings in a clear, relevant, and reliable way to individuals and communities most likely to benefit. The end result is a greater understanding of lifestyle and environmental factors influencing breast cancer risk.

**MISSION STATEMENT**

Zero Breast Cancer is a nonprofit organization dedicated to finding the causes of breast cancer through community participation in the research process. We focus on identifying environmental factors and the role they play in the initiation and progression of breast cancer at all stages of life and across generations.
The Search for Answers

In 1996, five of MBCW’s founding members attended the International Breast Cancer Conference in Canada, where they learned that the California Breast Cancer Research Program (CBCRP) would be giving out grants specifically for community-based participatory research projects developed through collaborations between researchers and community members.

The attendees returned from the conference determined to find an academic partner interested in doing research with them on the high incidence of breast cancer in Marin County. They began cold-calling epidemiologists, trying to find one who would work with them. Finally, Dr. Margaret Wrensch, an epidemiologist at the University of California, San Francisco agreed to meet with them and teach them about the research process. Dr. Wrensch expected that the women, who had no scientific credentials, would lose interest once they learned what was required. But as she came to realize, they were determined to educate themselves about the research process.

Working together, the group submitted a research proposal, and in 1998, they received one of the first community-based research projects funded by the CBCRP.

Their study, “Adolescent Risk Factors and the Development of Breast Cancer in Marin County” (ARFS), was designed to investigate whether adolescent experiences and exposures differed between 300 women who had developed breast cancer and 300 who had not. And it would have a long-term impact on breast cancer research in Marin.

WHAT IS COMMUNITY-BASED PARTICIPATORY RESEARCH?

Community-based participatory research is an approach to research in which members of a community identify a problem and then engage outside researchers in a collaboration that generates novel research questions, promotes co-learning, and achieves a balance between research and action. It helps to ensure that the research process is responsive to a community’s needs, and is therefore more likely to find practical, useful answers and solutions.
Adolescent Risk Factors and the Development of Breast Cancer in Marin County

The ARFS study was groundbreaking in many ways. It was one of the first to focus on adolescence as a “window of susceptibility”—a stage in normal development when exposures to potential carcinogens might affect breast cancer risk in later life. And it was the first to reveal population risk factors and exposures linked to breast cancer development in Marin County.

The first findings, which resulted in our first publication, appeared in Breast Cancer Research in April 2003. We reported that women in Marin who had developed breast cancer were more likely to have:

- been premenopausal
- never taken birth control pills
- a lower highest lifetime body mass index
- had four or more mammograms
- started drinking after the age of 21
- two or more glasses of alcohol per day, on average
- the highest quartile of pack-years of cigarette smoking
- been raised in an organized religion
- lived as adolescents in high socioeconomic families.

The study also found that women with and without breast cancer were equally likely to have a first-degree relative with breast cancer, a history of benign breast biopsy, or previous radiation exposures, or to have used hormone replacement therapy. Interestingly, the two groups also did not differ significantly in terms of their age at menarche, number of births, or years spent living in Marin. (Breast Cancer Research 5(2003)R88).

ARFS and the data it provided have informed future risk reduction and breast cancer research efforts. We used the findings to develop our Adolescent Breast Cancer Prevention, Risk Reduction, and Education Program, which created an internationally recognized peer education tool kit. In addition, researchers at the University of California, San Francisco, Stanford University in Palo Alto, and the University of Michigan conducted further analyses of the ARFS data. ARFS also laid the foundation for the funding and community participation necessary to conduct additional research studies, such as the Marin Women’s Study. It also lead to the establishment of the Bay Area Breast Cancer and the Environment Research Center.

WHAT WE MEAN WHEN WE TALK ABOUT THE ENVIRONMENT

At Zero Breast Cancer, our definition of “the environment” is broad. It includes lifestyle choices, foods and nutrients, and prescription drugs, as well as exposures to both natural and synthetic chemicals, toxins, and contaminants. We believe the best hope for the future health of our children and ourselves lies in primary prevention: identifying and eliminating breast cancer risk factors and exposures to carcinogenic toxins that are found in our air, water, soil, and food supply, and are now evident in our bodies and breast milk.
Marin Environmental Studies

In response to our community’s concerns about environmental exposures and breast cancer, we initiated two additional studies in Marin County. The first study, the Personal Environmental Risk Factors Pilot Study, conducted in 2002, received nearly 1,500 comments from Marin County residents that expressed 336 unique ideas about possible environmental exposures that may increase breast cancer risk. The potential risk factors most frequently mentioned were pesticides, water quality/contamination, and air contamination. The second study, the Marin Environmental Data Study, conducted in 2003, established a Marin County–specific environmental database by using publicly available datasets to identify, describe, and GIS map information on accidental toxic releases, pesticide usage, and air, water, and soil quality.

To date, ZBC has actively participated in 11 research studies that have enrolled Marin women and families or have focused geographically on Marin County and its environment. A summary of these studies, their findings, and most importantly, what the findings mean, can be found at www.zerobreastcancer.org/research.html.

Over the past 15 years, we have repeatedly seen our community express its interest in and willingness to help guide and take part in research efforts that will uncover the relationship between the environment and breast cancer in Marin County and beyond. This, in turn, has continued to solidify our commitment to expediting the research that will help us learn how we can prevent breast cancer.

HATS OFF TO PLEXUS ART GROUP

Zero Breast Cancer is pleased to announce the acquisition of a collection of one-of-a-kind hats created by the members of the Plexus Art Group.

Formed in 2007, the Plexus Art Group is composed of Bay Area artists who make and exhibit fine art that addresses social and political concerns directly impacting its members and the community at large.

The 38-hat collection was made in honor of fellow Plexus artist and emeritus ZBC board member Roni Peskin-Mentzer. After Roni learned that her breast cancer had returned, the group wanted to do something to support her, and Roni suggested that they create hats that would be beautiful pieces of art. The Plexus Art Group responded with enthusiasm, generosity, and creativity.

The hats, which are on display at the ZBC office, can be loaned out to community groups for use at fund-raising events, conferences, and community exhibits. For more information about how you can bring these hats to your event, please contact ZBC.
Collaborating with Researchers

Our efforts to engage the community in breast cancer research would not be possible without the collaborations we have developed with scientists and educators locally, regionally, and nationally. These collaborations have allowed us to see firsthand how science can benefit when researchers and advocates leverage their assets and professional skills to initiate and design research studies. They also have resulted in grant funding for research that has advanced our understanding of breast cancer while, simultaneously, establishing and promoting the value of community-based participatory research.

We are proud to be leaders in the effort to build relationships among researchers, breast cancer advocates, and the community.

Our past and current scientific collaborators include:

- **Christopher Benz, MD**, Buck Institute for Age Research, Novato, Calif.
- **Christine Erdmann, PhD**, University of Michigan, Ann Arbor, Mich.
- **Rochelle Eremann, MS, MPH**, Marin County Department of Health and Human Services, San Rafael, Calif.
- **Sibdas Ghosh, PhD**, Dominican University of California, San Rafael, Calif.
- **Joe Gray, PhD**, Lawrence Berkeley National Laboratory, Berkeley, Calif., and Oregon Health & Science University, Portland, Oregon.
- **Robert Hiatt, MD, PhD**, Helen Diller Family Comprehensive Cancer Center, University of California, San Francisco.
- **Lawrence Kushi, ScD**, Division of Research, Kaiser Permanente, Oakland, Calif.
- **Zena Werb, PhD**, University of California, San Francisco.
- **Margaret Wrensch, PhD**, University of California, San Francisco.

“Zero Breast Cancer makes it a point to learn about how research is conducted, to stay up with the literature, and to firmly articulate their views. Therefore, their effectiveness is maximized.”

—Robert Hiatt, MD, PhD, Deputy Director Helen Diller Family Comprehensive Cancer Center, University of California, San Francisco

Panelists at the 2008 Bay Area Breast Cancer and the Environment Research Center Town Hall Meeting in Oakland, Calif. Left to right: Larry Kushi, ScD; Zena Werb, PhD; Mary Helen Barcellos-Hoff, PhD; Paul Yaswen, PhD; and Robert Hiatt, MD, PhD.
In April 2002, ZBC was invited to the National Institute of Environmental Health Sciences (NIEHS) for a brainstorming session on breast cancer and the environment, chaired by Kenneth Olden, PhD, who was then NIEHS’s director. The workshop was held to gather input and insights from scientists, breast cancer advocates, consumers, and public interest groups that the NIEHS could work with as it developed centers that would provide vision, leadership, and coordination for the field of breast cancer research related to environmental factors.

Later that year, in partnership with the UC Berkeley Environmental Health Sciences Center, ZBC sponsored a town hall meeting in Marin with Dr. Olden on breast cancer and the environment. More than 200 scientists, breast cancer advocates, public health professionals, and community members attended the two-day meeting, “Voices for a Healthy Community,” to learn about breast cancer research and advocacy in the San Francisco Bay Area.

The town hall meeting was a success on many levels. It continued the dialogue with the community on breast cancer. It identified areas of future breast cancer research. And it created collaborations among breast cancer groups, health professionals, scientists, public policy advocates, government officials, and community members.

The meeting also resulted in two unexpected, yet extraordinary, outcomes. First, U.S. Congresswoman Lynn Woolsey announced that the directors of four of the nation’s top health research agencies—the National Cancer Institute, the National Institutes of Health, the Centers for Disease Control and Prevention (CDC), and the U.S. Department of Health and Human Services—had agreed to join forces to find out why Marin County’s breast cancer rate was the highest in the United States and perhaps the world. The directors vowed to assess the situation and determine which research strategies were most appropriate to reduce breast cancer incidence rates in Marin County. Due to their commitment, the CDC, for the first time, gave Marin County $500,000 to conduct breast cancer research. These funds lead to the development of the Marin Women’s Study, which Representative Woolsey has continued to actively support and secure funding for.

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ZBC EXECUTIVE DIRECTOR APPOINTED TO FEDERAL ADVISORY COMMITTEE

In October 2010, Zero Breast Cancer Executive Director Janice Barlow was invited to serve on a newly formed advisory committee that will develop and coordinate a strategic federal research agenda on environmental and genetic factors related to breast cancer.

Barlow is one of six advocates on the new 19-member Interagency Breast Cancer and Environmental Research Coordinating Committee. The committee, established by the National Institute of Environmental Health Sciences in collaboration with the National Cancer Institute, will review all research conducted or supported by federal agencies on environmental exposures and breast cancer. The committee also will develop recommendations for the Secretary of the U.S. Department of Health and Human Services, the National Institutes of Health, and other federal agencies on innovative research strategies.
SHAPING CANCER RESEARCH

Zero Breast Cancer is widely known for its commitment to bridging the gap between researchers and the community.

Our objectives are simple:

- To bring the voice of the community to the research process.
- To translate the research findings back to the community so the information can be used to make informed personal choices and better public policy.

To accomplish these objectives, we sponsor community forums, town hall meetings, and scientific conferences that facilitate a two-way communication between researchers and interested community members, and provide an opportunity for community members to share their concerns and research priorities.

When we first became involved in breast cancer research, we recognized that successful collaborations between researchers and the community would require both educating the community about what research studies can and cannot do, and explaining to researchers how their studies would benefit from community involvement.

Over time, we’ve seen skepticism give way to understanding—on both sides. And because of what we have learned and accomplished, we are frequently sought out by public officials and scientists who want to ensure that the community is involved in defining the research agenda.

ZBC currently serves on 11 breast cancer scientific and community advisory boards, addressing the spectrum of breast cancer research from prevention to personalized breast cancer treatment to survivorship. Our participation on these advisory boards ensures that the researchers ask the right questions and generate the most accurate and useful research findings.

*(For the full list, see Appendix A: Scientific and Community Advisory Boards: Expanding Our Influence, p. 28.)*
Bay Area Breast Cancer and the Environment Research Center

Our involvement with the Bay Area Breast Cancer and the Environment Research Center (BABCERC) included collaborative research with the three other BCERCs to determine how environmental factors may contribute to early puberty and to learn which exposures that occur during puberty may increase breast cancer risk later in life (see sidebar).

To date, four studies have been published by the BCERCs, and more publications are expected. The first study found higher levels of chemicals that act like hormones—flame retardants (PBDEs), pesticides, and polychlorinated biphenyls (PCBs)—in girls in the Bay Area than in a comparison group at a BCERC in Ohio (Environmental Research (2010), doi:10.1016/j.envres.2010.01.004). The second study, which analyzed urine samples from girls in three BCERCs—the San Francisco Bay Area, New York, and greater Cincinnati—found that phthalates, phenols, and phytoestrogens were detected in nearly all of the girls, and that higher exposures to some of the chemicals appeared to influence breast development. This study found links between the time when a girl’s breasts begin to develop and exposure to specific chemicals, and it received widespread media attention because it suggested that specific chemicals may influence the timing of pubertal development and, potentially, future breast cancer risk (Environmental Health Perspectives 7(2010)1039).

The third study found that more girls are now starting breast development at ages 7 and 8, compared to previous decades, when breast development occurred at a later age. This is the earliest age of pubertal development seen in any of the studies conducted on this topic over the past two decades (Pediatrics 126(2010)e583). The fourth study found that the start of puberty might be affected by whether a girl’s biological father lives at home, with girls living in homes without a biological father more likely to begin puberty at an earlier age (Journal of Adolescent Health doi:10.1016/j.jadohealth.2010.07.032).

Girls who are part of the CYGNET study at a Tea Talk held in 2006 at Kaiser Permanente Medical Center in San Rafael, Calif.

Dr. Robert Hiatt and a CYGNET participant at a Tea Talk held in 2007 at the Berkeley Museum of Health in Berkeley, Calif.
BAY AREA BREAST CANCER & THE ENVIRONMENT RESEARCH CENTER

In 2003, Zero Breast Cancer collaborated with Bay Area scientists to establish the Bay Area Breast Cancer and the Environment Research Center (BABCERC). Funded through a competitive awards process by the National Institute of Environmental Health Sciences (NIEHS) and the National Cancer Institute (NCI), the BABCERC was one of four centers that took part in a seven-year initiative to advance basic science and epidemiology research on potential environmental causes of breast cancer. The three other institutions that received these competitive awards were the University of Cincinnati, Fox Chase Cancer Center in Philadelphia, and Michigan State University in East Lansing. The four centers operated independently but worked collaboratively.

The BABCERC comprised three projects:

1. The Basic Science project conducted research on mice and human tissue to investigate how the breast develops and how that development is affected by environmental exposures.

2. The Epidemiology project, the “Cohort Study of Young Girls’ Nutrition, Environment, and Transitions” (CYGNET), followed a group of girls for six years as they went through puberty to investigate how, separately and together, genes, the environment, biology, lifestyle, socioeconomic factors, and body composition influence the age that puberty begins.

3. The Community Outreach project, chaired by ZBC, worked with the Basic Science and Epidemiology projects to integrate the community’s interests and concerns into the research agenda. This project was formally known as the Community Outreach and Transition Core (COTC).

The four centers were designed to be seven-year projects, and formally ended in July 2010. However, the studies that were conducted under the projects’ auspices are continuing. In recognition of our accomplishments and ongoing commitment to research translation, ZBC was awarded grants to be the community partner in two of the NIEHS/NCI research studies funded as part of the Breast Cancer and the Environment Research Program. These studies, “Breast Biology and Susceptibility through the Life Cycle” and the “CYGNET Study: Environmental and Genetic Determinants of Maturation of Girls,” will extend the research initiated by the BABCERC for an additional five years, to 2015.

To learn more about the Breast Cancer and the Environment Research Programs, visit the website www.bcerp.org. To learn more about the BABCERC, visit http://bayarea.bcerc.org.

WANT TO LEARN MORE?
Download the report Puberty, Breast Cancer, and the Environment from the BABCERC website, http://bayarea.bcerc.org. The report describes BABCERC’s Basic Science, Epidemiology, and Community Outreach projects. It explains why BABCERC explored the hypothesis that puberty is a “window of susceptibility,” a time during the life span when breast cells might be especially sensitive to potential carcinogens, which may in turn affect the risk of breast cancer in later life. And it illuminates what studying puberty may reveal about how breast cancer develops and how it can be prevented.
Marin Women’s Study

The Marin Women’s Study is a breast cancer research study funded by the CDC that is made possible by the continued efforts of Congresswoman Lynn Woolsey, Senator Barbara Boxer, and the Marin County Board of Supervisors.

The study is a highly collaborative project. It is spearheaded by the Epidemiology Team at the Marin County Department of Health and Human Services in partnership with the generous support of these steering committee members:

- Buck Institute for Age Research
- Cancer Prevention Institute of California
- Fred Hutchinson Cancer Research Center
- Kaiser Permanente Division of Research
- Kaiser Permanente San Rafael Medical Center
- Marin Cancer Institute at Marin General Hospital
- University of California, San Francisco
- Zero Breast Cancer

The Marin Women’s Study was open to all Marin County residents who received mammograms (both screening and diagnostic) between late 2006 and early 2010. Currently, only women receiving diagnostic mammograms have been invited to join. To date, approximately 14,000 women have enrolled in the study.

The first research results from the Marin Women’s Study, published in April 2010, highlight the relationship between hormone therapy and breast cancer incidence in Marin County. In particular, the paper shows that after a sharp reduction in the use of hormone therapy that included both estrogen and progesterone, the rates of invasive breast cancer declined in Marin by more than 33 percent (BioMed Central Public Health Journal 10 (2010) 228). (Similar studies showed similar results in women throughout the U.S.) This does not mean that Marin’s historically high breast cancer rates are due solely to the use of hormone replacement therapy. Rather, it suggests that the use of these hormones was an important piece of the puzzle—and that many other pieces remain to be found.

“Being ground zero for high rates of breast cancer in Marin County is nothing to applaud. The good news is that the collaborative and progressive work of many organizations, including Zero Breast Cancer, placed elimination of breast cancer as a top priority in our county. Working together, we are facing the problem head on and seeing important and meaningful changes.”

—Susan L. Adams, PhD, RN, Marin County Board of Supervisors, District 1

Marin County Department of Health and Human Services Epidemiology Team. Left to right: Mark Powell, MD; Kathy Koblick, MPH; Larry Meredith, PhD, (Director); Rochelle Ereman, MS, MPH; Chris Corniola, PhD. (Not pictured: Lee Ann Prebil, PhD)
Eliminating BREAST CANCER

We believe that the only way we will eliminate breast cancer is by engaging our community in the research process and collaborating with researchers to conduct the studies that will expedite our ability to identify the environmental factors that increase breast cancer risk in Marin County and beyond. Using the knowledge gained from this research, we can educate our community about how environmental factors play a role in the initiation and progression of breast cancer.

To achieve this goal, we have created innovative, research-based community education programs, tool kits, and breast cancer risk-reduction initiatives that community members, health professionals, and government officials can use to take action to prevent breast cancer and improve the overall health of our community.

“We need input from communities in setting the science agenda and in fostering positive partnerships . . . I look forward to the day when I can stand here with all of our partners to say, ‘We did it. We know how [breast cancer] happens, and we can stop it.’”

–Linda Birnbaum, PhD, Director of National Institute of Environmental Health Sciences

The community forum held in November 2009 at the Cavallo Point Lodge gave scientists and breast cancer advocates and survivors an opportunity to engage in discussions on environmental factors related to breast cancer.
Community Education Programs

Zero Breast Cancer has sponsored more than 45 community forums and town hall meetings on breast cancer and prevention. These include:

- *Focus on Breast Cancer in Marin* (2009)
- *The Promise of Stem Cells in Human Health* (2009)
- *Positive Effects of Physical Activity* (2007)
- *Stress and Breast Cancer* (2005)

These programs have allowed us to bring the community's voice to researchers. They also have allowed scientists to disseminate their most recent research findings to the public so that individuals and communities can take immediate action to reduce their breast cancer risk.

“One of the things I really love about working with Kaiser is that Kaiser’s focus isn’t just on the health of its members but the health of the community at large—and ZBC also embraces that. So it’s a natural fit for us to work together. I also like the forums and educational opportunities that ZBC provides for the community.”

—Mary Beth Faustine, Manager, Cancer Support Program, Kaiser Permanente, San Rafael
COMMUNITY FORUM: BREAST CANCER AND THE ENVIRONMENT

One of the hallmarks of ZBC’s work is our community meetings and forums.

In November 2009, as chair of the BABCERC, we invited Dr. Linda Birnbaum, director of the National Institute of Environmental Health Sciences, to be the guest speaker at the forum “Breast Cancer and the Environment: From Research to Action.” This proved to be one of our most memorable town hall meetings.

Dr. Birnbaum explained to the audience that although studying environmental factors related to breast cancer may be difficult, it is necessary and critical that we fully understand how chemicals and other toxins in our environment may increase breast cancer risk.

Following her talk, Dr. Birnbaum joined a distinguished panel that included Gwen Collman, PhD, interim director of the Division of Extramural Research and Training at NIEHS; Janice Barlow, MSN, executive director of Zero Breast Cancer; Rupali Das, MD, chief of the Exposure Assessment Section in the Environmental Health Investigations Branch of the California Department of Public Health; Peggy Reynolds, PhD, senior research scientist at the Northern California Cancer Center; and Jeanne Rizzo, RN, president and CEO of the Breast Cancer Fund.

Public participation is always encouraged at our forums, and the panel engaged in a frank and open discussion with community members, addressing topics that ranged from environmental risk factors and public health policies to community needs in ongoing breast cancer research. “Public participation can change the direction of the research,” said Barlow. “When a community is involved from the beginning, it influences not only the questions that are being asked but how the community responds to and what it does with the findings.”
Adolescent Breast Cancer Prevention, Risk Reduction, and Education Program

ZBC used the findings from the ARFS study to develop an adolescent peer education breast cancer prevention, risk reduction, and education program. This work led to the development of our Adolescent Peer Education Tool Kit, which was first piloted in a Marin County high school’s social issues and health class. Today, the module not only continues to be used in Marin County high schools, but has been used as a model to help develop youth education programs in the Bay Area, throughout the United States and Canada, and as far away as New South Wales, Australia.

“We are very keen on the Peer Education Tool Kit . . . This is a model that we are studying in our efforts to develop a national curriculum to educate young Australian women to be more breast aware.”

—Helen Paynter, Education Director, McGrath Foundation, New South Wales

HOW TO REDUCE YOUR EXPOSURE TO ENVIRONMENTAL CHEMICALS

- Use glass containers in the microwave.
- Ask for dry cleaning services that do not use PERC, or ask for “wet cleaning.”
- Take time to read labels, and avoid phthalates and “fragrance” in products.
- When grilling food, minimize “char” by reducing the heat level and/or using marinades.
- Purchase organic foods when possible, and encourage stores you patronize to expand their selection of organic foods.
- Monitor what chemicals are put down the drain in your home.
- Not all vacuum cleaners are created equal. Get one with strong suction, a multilayered bag for dust collection, and a HEPA filter.
- Look for electronic equipment and furniture without PBDEs.
- Use organic practices for gardening and lawn care, and encourage your neighbors to do the same.
- Encourage your town to adopt policies of using natural and nontoxic solvents in public buildings and organic practices in the care of green spaces.

SOURCE: Information developed by the Silent Spring Institute and reprinted with permission.

This map represents the geographical reach of Zero Breast Cancer’s Adolescent Peer Education Program.
Latina Outreach Program

In 2006, ZBC partnered with bilingual, bicultural students, educators, and consultants to create our Latina Adolescent Outreach Project and to develop a culturally tailored bilingual breast cancer information brochure for Latina teens, young women, and families, modeled on our successful Adolescent Peer Education Tool Kit. The public health impact of this project was recognized at the poster session at the 2008 BCERC annual conference, and was subsequently presented at the prevention panel of the 2010 National Latino Cancer Summit.

We have continued to expand our capacity to promote the Latina Adolescent Outreach Project by engaging with the local and national Hispanic/Latino community through conferences, media, health fairs, and youth outreach programs. We also work with a group of Latina youth advisors on Spanish-language promotion of the Latina project messages and information, which has included appearances on Encuentro Latino public access community television.

Since 2005, we have promoted the contributions of ZBC’s Latina youth advisors with the Marin Latino Council and the National Latino Cancer Summit, and their work has been recognized through awards programs such as ZBC’s Honor Thy Healer, the Martin Luther King Jr. Humanitarian Award, and the American Association of University Women Project Recognition Award.

“I am so fortunate to have been given the opportunity to become part of such an amazing organization at such a young age. I feel like I, as a teen, am making a big difference in this world because of everything that I am learning.”

—Daniela C., High School Senior, Novato

Attendees at the 2010 Breast Cancer Research and Latinas community forum held in the Canal Neighborhood of San Rafael, Calif.

Promotoras (health promoters) Alexandra Danino and Norma Ledezma discuss their work at the community forum.
Honor Thy Healer Program

This unique program provides an opportunity for ZBC to showcase its educational programs and research findings, as well as recognize individuals, businesses, and organizations that have played pivotal roles in advancing our understanding of breast cancer and the healing process.

Each year at our Honor Thy Healer Awards Celebration, ZBC recognizes five individuals and groups through our Community Breast Cancer Research Award, Francine Levien Activist Award, Healing Partner Award, Healing Professional Award, and Shining Star Award. The ultimate goal of Honor Thy Healer is to recognize everyday heroes who support those affected by breast cancer, pioneering breast cancer researchers and clinicians, and activists dedicated to improving the health of our communities. Proceeds from the program provide funding for a wide range of ZBC’s breast cancer prevention and educational efforts.

A complete list of ZBC’s Honor Thy Healer awardees can be found in Appendix B, p. 29.
**Educational Tool Kits**

As the lead community partner of the BABCERC, ZBC spearheaded the center’s Community Outreach and Transition Core (COTC), which developed and disseminated two basic science educational tool kits.

**Of Mice and Women: Modeling Breast Cancer and the Environment**

Our work with the BABCERC highlighted a need to educate women and men throughout the Bay Area about the role basic science plays in cancer research. As leaders of the COTC, we worked with Mary Helen Barcellos-Hoff, PhD, a member of the BABCERC basic science project who is currently at New York University, to develop the educational tool kit *Of Mice and Women: Modeling Breast Cancer and the Environment*. The kit includes a 35-minute DVD and an accompanying scientific glossary that explains in easy-to-understand terms how basic scientists pursue research questions and the advantages and disadvantages of using mice models to study breast cancer in humans.

*The Breast Biologues: A Biology Dialogue About Breast Cancer and the Environment*

This 15-minute animated video premiered in November 2010. Narrated by Emmy Award–winning actor Peter Coyote, *The Breast Biologues* uses time-lapse imaging to explain how the normal breast develops and how exposures to potential cancer-causing chemicals during specific periods of development might influence future breast cancer risk. In addition, comic books based on *The Breast Biologues* are available in English and Spanish. The comic books, which discuss the biology of the breast and the latest BABCERC research, can be used in conjunction with the video or on their own.

Both videos, *Of Mice and Women* and *The Breast Biologues*, and the comic books may be ordered by contacting ZBC.

“Your work gives us a jump-start to engage and inform the communities we serve about the relationships between the environment and health.”

—Barbara L. Brenner, DrPH, Associate Professor, Preventive Medicine, Mount Sinai School of Medicine, New York

“The science is complex. It can be challenging to explain. In *The Breast Biologues*, radiation is the example that helps explain how the environment can set precancerous cells in motion. It’s broken down into steps and illustrated.”

—Paul Yaswen, PhD, Lawrence Berkeley National Laboratory
Breast Cancer Risk Reduction Initiatives

Get Moving!

Breast cancer research findings suggest that physical activity throughout one’s life can reduce breast cancer risk. ZBC highlights the benefits of physical activity through two innovative programs:

Dipsea Hike/Run Lite

Annie Fox, a ZBC board member (1999–2002) and avid Dipsea trail runner, organized the first Dipsea Hike/Run in 2002. Sadly, Annie lost her battle with breast cancer at age 35 on the eve of the first run. Today, ZBC holds its annual Dipsea Hike/Run Lite, in partnership with the Tamalpa Runners, in Annie’s honor.

Hundreds of people from throughout the Bay Area participate in this community event. The course utilizes several of the trails on Mount Tamalpais, including the famous Dipsea steps. It is designed to accommodate both trail runners and hikers, and attracts everyone from school-aged children to people in their 70s and beyond.

The Dipsea Hike/Run Lite provides an opportunity for ZBC to educate the community about the research that has shown that exercise can reduce a woman’s breast cancer risk. Studies have also found that exercise may relieve cancer-related symptoms, improve quality of life, and reduce the risk of a breast cancer recurrence.

HOW TO REDUCE YOUR BREAST CANCER RISK

- Avoid gaining weight as an adult. Try to maintain a healthy weight for your body type.
- Limit alcoholic beverages.
- Use precaution with certain chemicals in cleaning agents, household products, and cosmetics.
- Be physically active—walk briskly or exercise for 30 minutes most days of the week.
- Include leafy green vegetables and whole grains in your diet, especially if you drink alcohol.
- Avoid using menopausal hormone therapy (estrogen and progesterone combined).
- Breastfeed your baby for as long as possible, ideally for a full year.
- Don’t smoke tobacco, and don’t let others smoke near you or your family at home or at work.
- Minimize radiation exposure, especially for girls and younger women. Talk to your doctor about reducing your exposure to medical radiation.
WHO KNEW?

Who knew kicking a soccer ball could decrease her risk of developing breast cancer?

In October 2010, ZBC launched an exciting new education campaign aimed at lowering girls’ future risk of developing breast cancer. The campaign includes eye-catching bus shelter posters and a portable pop-up banner that emphasize how beneficial it is for girls to maintain a healthy weight and stay physically active throughout their life span.

Why is this important? A review of 19 research studies focused on physical activity and breast cancer risk in adolescence and young adulthood found a nearly 20 percent difference in breast cancer risk between those who were the most active and those who were the least active. Researchers believe this is because breast cancer risk is directly related to the total number of ovulatory cycles a woman experiences during her lifetime. Studies suggest that adolescent girls who exercise may have fewer ovulatory cycles or may experience more menstrual cycles without ovulation. ZBC supports more research to fully understand the connection between physical activity and breast cancer risk.

HOW CAN YOU HELP YOUR DAUGHTER BECOME MORE ACTIVE?

1. Sign her up for a sport or activity she enjoys.

2. Incorporate physical fitness into family and everyday activities.

3. Limit her screen time to two hours or less per day. Screen time includes time spent watching TV, on a computer, or playing video games.

4. Be a role model for your daughter by being physically active yourself.
Conclusion

ZBC was started 15 years ago in response to the high incidence rates of invasive breast cancer in Marin County and the San Francisco Bay Area. While the incidence rates have varied over the years, there is little question that the rates in Marin County and the San Francisco Bay Area, as well as elsewhere, remain unacceptably high. (See the following page for history of incidence rates in Marin County.)

In our efforts to illuminate the connections between breast cancer and the environment, ZBC will continue to engage our community and express their concerns at the local, state, and federal levels; expedite the research that is necessary to discover the environmental factors that increase breast cancer risk; and help the community and public policy makers understand the actions each can take to achieve our ultimate goal of eliminating breast cancer.

“The message is that breast cancer is so very important because it affects our community as a whole and the community is saying . . . we do not want to accept this loss.”

—Laura Esserman, MD, Director, Carol Franc Buck Breast Care Center, University of California, San Francisco
Invasive Breast Cancer Incidence Rates in Marin County

Marin County has a history of elevated breast cancer incidence rates. The rates increase and decrease on an annual basis but have been consistently higher than those in other San Francisco Bay Area counties, California, and the United States. Below are the incidence and mortality rates for Marin County from 1988 to 2007, which are the most recent figures available.¹


1. On average, it takes 2–3 years for the registries to "clean" the data to ensure the figures are correct.

2. The incidence rates are age adjusted to ensure that breast cancer elevations are not due to a higher number of older women living in Marin and other counties. Age-adjusted rates make it possible to compare counties throughout the state.
Zero Breast Cancer TIMELINE

1995
> Researchers at the Northern California Cancer Center report that the SF Bay Area has the highest breast cancer rate in the world, and that Marin has the highest breast cancer rate in the Bay Area.
> Marin Breast Cancer Watch (MBCW) founded by Francine Levien and Wendy Tanowitz.

1996
> MBCW incorporated.

1997
> In collaboration with UCSF, MBCW launches the Adolescent Risk Factors Study (ARFS) funded by the California Breast Cancer Research Program.

1999
> First newsletter Keeping Abreast published.

2000
> First annual Honor Thy Healer program.

2002
> The Personal Environmental Risk Factors Study, Traditional Risk Factors Study, and the Marin Environmental Data Study are launched.
> In April ZBC was invited to the National Institute of Environmental Health Sciences (NIEHS) for a brainstorming session on breast cancer and the environment, chaired by Kenneth Olden, PhD, who was then NIEHS’s director.
> First annual Dipsea Hike/Run.

2003
> First publication: ARFS findings published in the peer-reviewed journal Breast Cancer Research.
> Bay Area Breast Cancer and the Environment Research Center established.
> San Francisco Foundation grant for Diverse Communities Outreach Project awarded to ZBC.

2004
> In collaboration with the Northern California Kaiser Permanente Division of Research, ZBC launches “The Pathways Study: A Prospective Study of Breast Cancer Survivorship.”
> ZBC initiates the Adolescent Breast Cancer Prevention, Risk Reduction, and Educational Program.

“Francine Levien would be amazed to see how Zero Breast Cancer has evolved from a grassroots group of women with breast cancer to the organization that it is today.”

—Caroline “Kit” Everts, ZBC Donor, Mill Valley
2005
> MBCW sponsors community forum: “Stress and Breast Cancer.”

2006
> MBCW adopts new name, Zero Breast Cancer, and logo.
> Adolescent Peer Education Tool Kit developed.
> In partnership with BioMedware, ZBC receives NCI funding as the community partner for the study “Cancer Clustering for Residential Histories.”

2007
> ZBC sponsors community forum: “Positive Effects of Physical Activity on Breast Cancer Risk.”
> ZBC serves as community partner on the study “Toward a New Paradigm of Breast Cancer Causation and Prevention.”

2008
> First Racing for Research fundraiser at Infineon Raceway to benefit ZBC.
> Latina Adolescent Outreach program launched.

2009
> In partnership with the UCSF-San Francisco General Hospital Avon Program, ZBC sponsors the “Breast Cancer Prevention Forum for Younger Women.”
> In partnership with Hadassah, Buck Institute for Age Research, Marin County Department of Health and Human Services, and Marin General Hospital, ZBC sponsors the community forum “Focus on Breast Cancer in Marin.”
> Invited to be the community partner for a Stand Up to Cancer “Dream Team” studying targeted cancer therapies.
> Town Hall Meeting with NIEHS Director Dr. Linda Birnbaum: “Breast Cancer and the Environment: From Research to Action.”

2010
> Tenth anniversary of Honor Thy Healer program.
> Launch of ZBC fall campaign to educate the public on the benefits of physical activity in reducing breast cancer risk.

2010–2015
> Community partner on two NIEHS research studies, “Breast Biology and Susceptibility through the Life Cycle.” and the “CYGNET Study: Environmental and Genetic Determinants of Maturation of Girls.”
Acknowledgments

**Founding Members**
Marin Breast Cancer Watch
Francine Levien
Wendy Tanowitz
Mary Gould
Chris Mason
Karen Evans
Lucille Pearson
Lucy Gerrard
Susan Weiner
Lisa Haden
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APPENDIX A

Scientific and Community Advisory Boards: Expanding Our Influence

Zero Breast Cancer is a member of the following scientific and community advisory boards.

**BREAST CANCER PREVENTION**


- Community Advisory Board to the UCSF Helen Diller Family Comprehensive Cancer Center (2006–present).


- Marin County Women’s Health Study’s Scientific and Community Advisory Board Steering Committee (2004–present).

**BREAST CANCER SURVIVORSHIP**

- UCSF SPORE Breast Cancer Advocacy Core (BSAC) (2004–present)


**PERSONALIZED BREAST CANCER TREATMENT**

APPENDIX B
Honor Thy Healer Awardees

2011
Krista Muirhead, MD, Chief of Oncology, Kaiser Permanente San Rafael Medical Center; Mary Helen Barcellos-Hoff, PhD, NYU Langone School of Medicine, Zena Werb, PhD, UCSF, and Paul Yaswen, PhD, Lawrence Berkeley National Laboratory, Bay Area Breast Cancer and the Environment Research Center; Patricia Kendall, Medical Group Administrator, Kaiser Permanente San Rafael Medical Center; Kim Juarez, Founder, LOLA / Living Our Lives Actively; Susan Mulvey.

2010
Oncology Nursing Team, Kaiser Permanente San Rafael Medical Center; Radiation Therapists, Marin Cancer Institute at Marin General Hospital; Jackson’s Hardware; Joe Gray, PhD, Lawrence Berkeley National Laboratory; Pam Marcus and Daren Joy, Lifefactory, Inc; Catherine O’Neill.

2009
Edward W. Banks, MD, Surgeon, Kaiser Permanente San Rafael Medical Center; The Safeway Foundation; Kathie Dalessandri, MD, Physician-Scientist; Karl Huie, Pacific Heights Cleaners, Sausalito; Walt Spicer.

2008
Bobbie Head, MD, PhD, Medical Oncologist, California Cancer Care; Marc Hurlbert, PhD, Director, Avon Foundation Breast Cancer Crusade; Marion H.E. Kavanaugh-Lynch, MD, MPH, Director, California Breast Cancer Research Program; Ysabel Duron, Founder & Executive Director, Latinas Contra Cancer; Leanne Greentree.

2007
Cindi Cantril, RN, ONC, MPH, Marin Cancer Institute at Marin General Hospital; Gordon Manashil, MD, Physician-in-Chief, Kaiser Permanente San Rafael Medical Center; Larry Meredith, PhD, Rochelle Ereman, MS, MPH, Kathy Koblick, MPH, Lee Ann Prebil, PhD, Mark Powell, MD, Chris Corniola, MPH, Marin County Dept of Health & Human Services, Larry Kushi, ScD, Kaiser Permanente Division of Research; Stephen Joseph; Daliah Neuberger.

2006
Richard J. Cohen, MD, Consulting Oncologist, California Pacific Medical Center; Beth Crawford, MS, CG, Director of Clinical Services, UCSF Cancer Risk Program; Sir Francis Drake High School Peer Resource Team; Christopher C. Benz, MD, Buck Institute for Age Research; Lloyd William Eichhorn.

2005
Lloyd Miyawaki, MD, MPH, Medical Director, Marin Cancer Institute; Mary Mockus, MD, PhD, Attending Surgeon, Kaiser Permanente San Rafael Medical Center; Gabriela Yamilet Orantes, Breast Health Outreach Advocate, Sigma Theta Psi; Robert A. Hiatt, MD, PhD, UCSF Comprehensive Cancer Center; Tina Action Programs of West Marin; Marin Man to Man.

2004
Laura Esserman, MD, Carol Franc Buck Breast Care Center, UCSF; Mary Beth Faustine, MS, Kaiser Permanente San Rafael Medical Center; Rosamaria Hayden, Marin Breast Health Connection; Colleen Kleier, Redwood High School; Peggy Reynolds, PhD, California Department of Health Services; Amy Shaw, MD, Sutter Medical Center, Santa Rosa; Cathy Tobin.

2003
Alison Smith, MD, North Bay Surgical Group; Kathleen Clark, Marin Breast Cancer Council; Bill Daniels, United Markets; Leslie Davenport, Institute for Health and Healing; Georgianna Farren, MD, Marin Community Clinic; Cheryl Lingvall; Margaret Wrensch, PhD, UCSF; The Theresa Wootton Family: Nancy Hansbery, Maria Howard, Renee Howard, and Onnie Kyne.

2002
Anne DeLaney, MD, Karin Szarvas-Kidd, RN, Kathy Givens, RNP, Kaiser Permanente San Rafael Medical Center Plastic & Reconstructive Surgery Team; Andrea Martin, Breast Cancer Fund; Roger Grossman, Marin Independent Journal; Connie Dean; Alvy Greenfield; Linda Trenholm.

2001
Francine Halberg, MD, Radiation Oncology, Marin General Hospital; Jan Zeller, RN; Anna Halprin, Tamalpa Institute; Jean Marie Murphy, Taking Refuge; Greg Schelkun; David Parkinson; Karen Wold.

2000
David Lakes, MD, Medical Oncology, Kaiser Permanente San Rafael Medical Center; Michael Broffman, Pine Street Clinic; Sandy Truex, RN, Marin Breast Health Center, Marin General Hospital; Nora O’Toole.
APPENDIX C
References


