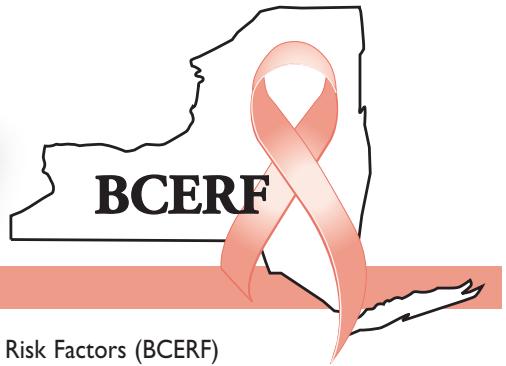


The Ribbon



Volume 9 • Number 2 • Spring 2004

A Newsletter of the Cornell University Program on Breast Cancer and Environmental Risk Factors (BCERF)

The Environmental Breast Cancer Movement

**Sabrina McCormick (Brown University),
Phil Brown (Brown University),
and Stephen Zavestoski (University of San Francisco)**

Editors note: This piece is an edited version of a longer article analyzing what the authors have called the environmental breast cancer movement. Their sociological research, based on interviews and observations, seeks to situate their findings and analyses of this movement within social movements theory. For The Ribbon version, we have focused on those aspects of the work which describe the origins, nature, and contributions of the environmental breast cancer movement, and to provide just a taste of how social scientists are finding interest in and focusing research on breast cancer activism. For a more thorough understanding of this work, please contact the authors for the complete paper: sabrina_mccormick@brown.edu

Since the early 1990s, the breast cancer movement has advanced a new public paradigm centered on environmental causes of breast cancer. We describe the framework, history, and strategies of that new national environmental breast cancer movement, and demonstrate the new concept of a “boundary movement.”

Breast cancer surfaced on the public agenda in the 1970s and 1980s on the second wave of feminism, as women began to present their personal stories of the disease to the public. It slowly moved from being conceived of as a private experience that could be overcome with a positive attitude and a supportive family, to being politically relevant, especially in terms of options for treatment. As women gained more control over treatment options, a breast cancer advocacy movement emerged, focused on increasing research funding and finding a cure for the disease. While activists criticized the medical control of their bodies, they at first did not challenge the biomedical model that focused breast cancer research on methods for treatment, constrained medical strategies to

lessen the possibility of getting breast cancer, and promoted individualistic methods for cancer prevention. As the breast cancer movement became more powerful, and the environmental movement put more attention on health effects of toxics, a new breast cancer movement that combined the two emerged to challenge the biomedical model and present what we term a new “public paradigm.”

The Environmental Breast Cancer Movement as a Boundary Movement

The public paradigm promoted by the environmental breast cancer movement focuses on the health effects of environmental toxins. Our notion of a public paradigm builds upon Krimsky's (2000) concept of a “public hypothesis” that is formed when the public feels it has a stake in scientific study, debates and consequent outcomes, and therefore demands to participate. In this case, activists base their new paradigm on the precautionary principle, which places the burden of proof for health effects of chemicals on the producers rather than the consumers, and declares that proof of safety should exist before chemicals are utilized (Raffensperger and Tickner, 1999). In order to do this, the environmental breast cancer movement works towards four goals: 1) to broaden public awareness of potential environmental causes of breast cancer; 2) to increase research into environmental causes of breast cancer; 3) to create policy which could prevent environmental causes of breast cancer; and 4) to increase activist participation in research¹. Creating a new public paradigm necessitates participation in science, and at least symbolic influence over its formation.

continued on page 2

¹ By environmental, we mean the effects of toxic substances (primarily chemical) in people's immediate or proximate surroundings.

index

Research Commentary:

Are Antibiotics
Linked to Breast
Cancer Risk? • 6

Activist Update:
The History of the
Breast Cancer
Mapping Project • 10

BCERF Regional
Cancer and
Environment
Forum • 8

Such influence requires a unique type of social movement—what we term boundary movements. Boundary movements are social movements and their constituent organizations that move between social worlds and realms of knowledge. In so doing, they blur traditional distinctions, such as those between movement and non-movement “actors” and laypeople and professionals. In particular, four characteristics define boundary movements.

First, they attempt to reconstruct the lines that demarcate science from non-science. They push science in new directions, and participate in scientific processes as a means of bringing previously unaddressed issues and concerns to the clinical and bench scientists.

Second, boundary movements blur the boundary between experts and laypeople. Some activists informally become experts by using the Internet and other resources to arm themselves with medical and scientific knowledge that can be employed in conflicts with their medical care providers. Others gain a more legitimate form of expertise by working with scientists and medical experts to gain a better level of understanding of the science underlying their disease. Through this process, boundary organizations gain power and authority by obscuring the boundary between expert and layperson.

Third, boundary movements transcend the traditional conceptions of what is or is not a social movement. They do this by moving fluidly between lay and expert identities, and across various organizational forms. Their fluidity allows them to move in and out of organizations and institutions in ways that traditional social movement activists do not. Raising money to fund their own research exemplifies how they are boundary organizations, since doing so blurs the boundary between previously distinct and autonomous institutions: science and civil society.

A fourth characteristic of boundary movements is that they use boundary “objects” (Star and Griesemer, 1989), things or activities that overlap different social worlds and are malleable enough to be used by different parties. Mammography machines, genetic testing for breast cancer, patents on the BRCA-1 sequence, pharmaceuticals, Breast Cancer Awareness Month, and Avon’s “Breast Cancer Walk” are such boundary objects that have a redefined role in the environmental breast cancer movement. These things and activities transect a variety of contexts, maintaining enough meaning similarity in each to create coherence across circumstances while being used distinctly in each one.

A boundary movement crosses two or more social movements, while blurring the boundaries of those separate movements. They take the best from surrounding movements, and also draw on the crossing over of

members from one organization to another and from one movement to another. Because ideas, values, and action strategies move from one movement to another, people find it easier to participate in other groups and movements. (Alternately, individuals can identify with and participate in such a movement, without having to be part of a specific organization.) The interaction among boundary movement organizations and groups is made possible by the fluidity with which these groups can move back and forth between organizational cultures, and between the roles of activists and experts. This fluidity allows professionals to play varying roles over time, occasionally being part of the movement as either members or “advocacy scientists” (Krimsky, 2000), other times being somewhat detached scientists, and other times being uninvolved.

Environmental breast cancer movement actors in different locations have a variety of relationships with the state, other movements, or experts, while maintaining a unifying movement philosophy. In our research we found that activists in one region found it easy to work with mainstream politicians, while others were more likely to link up with AIDS, women’s health, and toxics activists, and yet others found allies among those involved in precautionary principle organizing. Local context shapes the way each area approaches the problem, even though they are all part of one overall social movement.

Social and Scientific Construction of The Breast Cancer Epidemic

Breast cancer rates have been increasing steadily for at least fifty years, to the point where in the United States a woman is diagnosed with breast cancer every three minutes and another woman will die of breast cancer every twelve minutes. There will be an estimated 211,300 new cases of invasive breast cancer and 55,700 cases of *in situ* breast cancer diagnosed this year alone (American Cancer Society, 2003), and it is the leading cause of death for women under the age of 55. Due to public attention in the past twenty years largely caused by the breast cancer movement, the popular conception of breast cancer has changed radically from a private occurrence to a politicized experience. The breast cancer movement has addressed issues of care for breast cancer patients, knowledge about treatment options (especially in regard to mastectomies, lumpectomies and radiation), support for those affected by the disease, and increased research funding. Current government action includes the partnership between government and non-government sectors in the National Action Plan on Breast Cancer, established by President Clinton in 1994, among other projects. Private sector action includes the first National Breast Cancer Awareness Month, which promotes public awareness

of breast cancer and usage of mammography as early detection, first held in 1985. Today, fundraising walks and runs during that month involve tens of thousands of people every year. The movement's other successes include the production of a breast cancer stamp, whose additional cost above normal postage is given to governmental research institutions to further breast cancer research, and the Shop for the Cure campaign, whose merchants and credit card companies give a portion of the proceeds to breast cancer foundations. The general breast cancer movement's success can also be seen in the amount of breast cancer research dollars, which have increased from \$90 million in 1990 to \$600 million in 1999 (Reiss and Martin, 2000), and in the ability to win federal legislation, such as the Breast and Cervical Cancer Treatment Act of 2000.

The environmental breast cancer movement has reframed the successes of the broader breast cancer movement in order to focus on potential environmental causes and change how breast cancer is researched and publicly perceived. Some of those general movement successes are criticized by the environmental breast cancer movement, or by what Barbara Brenner (2000) terms the "political breast cancer movement."² For example, for years people took for granted the position of the American Cancer Society, National Cancer Institute, and other parts of the "cancer establishment" that "mammography is the best form of prevention." Environmental breast cancer activists argue that once a tumor is detected prevention has failed since the tumor now exists. Activists are also challenging the corporate control of Breast Cancer Awareness Month, and have mounted a campaign to have breast cancer stamp revenues shifted to the National Institute of Environmental Health Sciences from the National Cancer Institute.

Concurrent to the change in social perception, there has been scientific debate concerning the causes and treatment of breast cancer. The dominant scientific paradigms used in studying breast cancer have been circumscribed by the biomedical model and have consequently focused on individual level factors like diet, exercise, age at first birth, and genetic makeup (Kant *et al.*, 2000; Thompson, 1992). However, these studies have also shown that such factors account for a limited number of cases. The discovery of the BRCA-1 gene mutation led to

a large amount of attention devoted to genetic causes even though it has since been recognized that genetic causes only account for some five to ten percent of all cases (Davis and Bradlow, 1995). Activists also point to the fact the genome does not change rapidly enough to account for the increase in breast cancer incidence which, for women who lived to be age eighty, was 1 in 20 in 1964 and is now 1 in 8 over a lifetime.

A growing body of scientific literature has been exploring environmental causes of breast cancer. First these studies showed support for environmental causation, as in the case of Hunter's 1993 study that correlated DDE, the chemical breakdown product of DDT, a pesticide commonly used worldwide, and increased risk of breast cancer. Later studies (Wolff *et al.*, 1993;

Hunter *et al.*, 1997) showed equivocal results. The most recent research has demonstrated the complexity of studying breast cancer causes by using different types of evidence, such as twin studies (Lichtenstein *et al.*, 2000) and specific groupings or breakdowns of chemicals (Dorgan *et al.*, 1999; Hoyer *et al.*, 1999; Hoyer *et al.*, 2000; Guttes *et al.*, 1998). These studies demonstrate the wide scientific dialogue taking place around the legitimacy of claims pointing to environmental contaminants and increased

breast cancer risk.

New breast cancer research employing innovative methods and lay involvement has been promoted by breast cancer activists dedicated to investigating potential environmental causes. The three areas we examined – the San Francisco Bay area, the Boston/Cape Cod area in Massachusetts, and Long Island, New York – have higher breast cancer incidence than much of the rest of the United States, and public attention has led to numerous studies of these areas (Aschengrau *et al.*, 1996; Robbins *et al.*, 1997; West *et al.*, 1998). A combination of local and national contextual factors influenced the development of the movement, research, and policy in each location. Local factors include media response, the political climate and political connections, pre-existing social movements, the response of the local governmental institutions, and potential funding sources. A general movement framework unites the three locales into a national movement.

continued on page 4

² Our terminology for this movement was discussed with movement actors. They generally agreed that the term "environmental breast cancer movement" is appropriate. However, as evidenced by Brenner's terminology, there is some differentiation in naming the movement.

Study Methods

We conducted 29 semi-structured interviews with activists and scientists in movement organizations in the three previously mentioned locations, and with scientists in those locations. A site was operationalized by the existence of multiple activist organizations promoting increased public and scientific awareness of environmental causes of breast cancer and citizen/science alliances between these activists and scientists. Such scientists were interviewed in addition to activists. Ethnographic observations (11) were conducted to supplement the interviews, primarily at Silent Spring Institute in Newton, MA. These included public meetings where the researchers presented their work and their larger perspective, scientific review panel meetings, and science/activist conferences. While the interviews were the primary source of analysis, the observations provided a broader contextual picture. For instance, it was possible to view the approaches taken by Silent Spring Institute to bring their scientific work to lay activist audiences, or in another case, to see how Silent Spring responded to critics at a scientific review panel. Printed materials from each organization were also collected in order to better understand their political stance and public activities.

The Framework for Activism – Personal/Scientific/Political

Our interviews with activists demonstrate the importance of the personal experience as a political and scientific tool for the movement as a whole. Activist knowledge of self-exposure to environmental toxics first led them to a new form of movement activity and second, to challenging scientific perceptions of breast cancer. Our data show that activists believe clinical and support services are crucial, but not enough. For example, the traditional breast cancer movement response is to provide support groups which give emotional sustenance, while the environmental breast cancer movement emphasizes a model of political action which facilitates empowerment in the political realm, replacing the primary focus on individual responsibility with a focus on the responsibility of corporations, government institutions and science.

All interviewees, both scientists and activists, reported a strong belief that activism and social movements play a critical role in advancing research, educating the public, and changing policy about environmental causes of breast cancer. Activists felt that social movements were especially instrumental to the development of research into environmental causation. One long-time activist emphasized the difference between the activist and scientific perspective:

“Changes that have to happen around breast cancer and all the things that influence it are going to come from the ground up. They’re not going to come from the top down ... If you think about it, activists were the first to argue for this, and some of the scientific community has been sort of dragged along.”

Empowerment and politicization for movement activists often involves utilizing knowledge of individual environmental exposures to inform science. One example is the citizen/science alliance where scientists collaborate with community groups to search for potential environmental causation of diseases (more detail below). Another example is how epidemiologists teach lay activists enough science so that they can engage with scientists and officials, as with the National Breast Cancer Coalition’s Project LEAD (Leadership, Education, and Advocacy Development), where epidemiologists provide breast cancer activists with sufficient scientific capacity to serve on federal review panels (Dickersin *et al.*, 2001). Such a program helps facilitate a process of boundary crossing to advance science and make lay claims related to environmental causation credible in the eyes of science.

Social Movement Links to Environmental Breast Cancer Activism

The “personal as political” framework brings together multiple social movement perspectives in order to highlight the political and economic issues in breast cancer causation, research, and treatment, to challenge traditional epidemiological models, and to draw attention to unrecognized geographic disease patterns. The environmental breast cancer movement appears to be a merging of actors and agendas from the environmental movement and the breast cancer advocacy movement, and is rooted in the larger feminist movement, the women’s health movement, and the AIDS movement. This hybridization of movement activity is representative of the boundary crossing that movement actors have accomplished without diminishing the distinct nature of their own agendas.

By the time the environmental breast cancer movement had begun in the early 1990s, the national breast cancer movement had already achieved major successes in several different venues. In fact, the first breast cancer movement activity took place in 1952 in the form of Reach for Recovery, a self-help organization (Weisman, 1998). Breast cancer activism took further shape in the 1970s and ‘80s as a part of the general women’s health movement. In each one of the locales that we analyze, general breast cancer organizations preceded the develop-

ment of the environmental breast cancer movement and these activists often emerged from the general breast cancer movement. Their organizational strength also partially emerged from connections to the National Breast Cancer Coalition, and other previously established organizations. The origination of the movement in the breast cancer movement has simultaneously provided a strong basis of activism from which to organize, and some tension between movement actors as the philosophy of the movement has moved away from that of general breast cancer activism. Interviews with activists showed that despite these differences, there was a clear linkage between the former and latter movements.

The environmental movement provided legitimacy for environmental causation theories and offered an environmental activist network that could provide support. As environmental activists became more sophisticated in focusing on health effects, this provided a logical basis for connecting to breast cancer activism. The awareness created by a national grassroots environmental movement provided a basis from which the public could understand potential environmental causation and from which government could recognize a constituency of voters. The movement also emerged from the previous women's health movement that has worked to increase funding for research on women's illnesses, to educate women about their bodies, to include women in clinical trials, to criticize the medicalization of women's experiences, and to fight for self-determination of health care options (Ruzek *et al.*, 1997). While the environmental breast cancer movement is primarily concerned with a single disease, it broadens the implications of a health movement to address environmental issues, lay involvement in science, and corporate responsibility.

The environmental breast cancer movement benefited from the feminist movement in terms of increased public attention to women's issues, existing mobilized women's groups, tactics for activism, and ideological foundations. Feminism has been instrumental in developing a critique of both the lack of women's involvement in science, and the construction of knowledge that does not consider women's experiences. While most movement activists do not articulate a direct link between this movement and the broader women's movement, such a connection is often very clear through their philosophical stance and groups' mission statements. For instance, one founder of a movement group, also involved in a network of envi-

ronmental organizations, called breast cancer a wedge issue for larger gender equality and environmental issues:

"We want to share leadership, and bringing ourselves [women] into balance in this issue will help to bring the whole planet into balance. I do think that environmental health, using breast cancer as a wedge issue towards that larger issue, is the issue of the millennium."

While they generally did not connect their activities to feminism, some activists did note how the AIDS movement influenced their methods. The AIDS movement has been an exemplary model for activists in the movement in terms of citizen/science alliances, as well as public education and social protest. The methods utilized by AIDS activists, such as working with researchers to change scientific study, provided an example for future breast cancer activism. Additionally, like the environmental breast cancer movement, AIDS activists have utilized public protest tactics to subvert the social perception of AIDS victims, as well as generating more funds for research and activist involvement in research (Epstein, 1998).

While the environmental breast cancer movement is primarily concerned with a single disease, it broadens the implications of a health movement to address environmental issues, lay involvement in science, and corporate responsibility.

Citizen/Science Alliances

The citizen/science alliance specifically exemplifies the "analytical blurrings" that take place through boundary movements. Expert and lay roles are altered and typically rigid scientific practices take a new form as a result of these blurrings. The citizen/science alliance serves a key role by: 1) supporting activism; 2) changing attitudes and practices of scientists and activists; and 3) providing a new value structure to some research.

These collaborations between citizens and scientists have had ramifications for research, as well as perceptions of scientists and activists. Activists described drastic changes in their expectations about what science could prove in terms of environmental causation, their perception of the length of time necessary to conduct research, and the processes involved. They often became so educated about the methodology involved that they had specific recommendations for ways science could be improved in the future. Such education includes the National Breast Cancer Coalition's Project LEAD, which offers intensive orientation programs for advocates to

continued on page 8

Are Antibiotics Linked to Breast Cancer Risk?

Barbour S. Warren, PhD and Carol M. Devine, PhD

RECENTLY THE POPULAR PRESS WAS FLOODED WITH REPORTS OF ANOTHER POTENTIAL BREAST CANCER RISK FACTOR: ANTIBIOTIC USE.

The study which prompted all this attention was published in the mid-February issue of the Journal of the American Medical Association (JAMA)¹. This report found that antibiotic use was associated with more than a two-fold increase in breast cancer risk for women with the highest number of prescriptions of antibiotics, relative to women who were never prescribed antibiotics. Following the resulting barrage in the press, undoubtedly many women came to wonder, what is the meaning of this? They were not alone, as this question was the title of an editorial that accompanied the report in JAMA², a journal published primarily for physicians and researchers. The following discussion will address the meaning of this study and the potential for high antibiotic use to be an actual risk factor for breast cancer.

The Bottom Line

A good deal more study is needed before this relationship is established. Only two studies have addressed this question^{1,3}. Both studies reported an association between breast cancer and antibiotic use. However, these two studies do not provide a body of evidence which is strong enough to make a definitive conclusion about this association.

Nonetheless, these results are important. Antibiotics are prescribed commonly and, if this asso-

ciation does prove to be solid, their contribution to breast cancer incidence could be significant. This study should also be welcomed as a reflection of breast cancer as an active area of research in which potential risk factors are being pursued.

Studies that have examined this possible relationship

The first of the two studies that examined antibiotic use and breast cancer risk was a cohort study published in 2000.³ This study tracked women from 12 cities in Finland and evaluated those who had ever used antibiotics for urinary tract infections. From the 157 breast cancer cases that arose in this group of 9,461 women, a significant positive association between antibiotic use for urinary tract infections and breast cancer risk was found. This association only existed for women less than 50 years old; no association was seen for older women. In these studies, the under 50 group of women treated with antibiotics had a breast cancer risk which was 1.74 times that of the women who had not been treated for urinary tract infections. This was a preliminary study. It was small in size, looked at only one type of antibiotic treatment and did not carry out any detailed analyses.

The 2004 JAMA study was larger and more comprehensive and used a different study design. It

was a case control study of women in a large non-profit health plan in Washington State. The health plan's pharmacy records were used to determine antibiotic use for *any* condition for 2,266 women with existing breast cancer and 7,953 women without breast cancer. This study reported a 2.3 fold increase in breast cancer risk among women of all ages who had received the largest number of antibiotic prescriptions (more than 51 prescriptions over the period of up to 24 years). This result was statistically significant and was found for *both* premenopausal and post-menopausal women (risk values were not given for either of these groups individually). The results were further strengthened by the finding that breast cancer risk increased with prescription number in an exposure dependent manner (i.e. women with fewer prescriptions had lower risk and women with more prescriptions had higher risk). In addition, these investigators looked at the six different classes of antibiotics and found an exposure dependent increase in risk associated with all of them.

But this study was not without its flaws. These investigators did not report results which took into account the differences in the levels of established breast cancer risk factors which existed between the groups of women used for the comparison. They stated that such an analysis was conducted but they chose only to report the results which accounted for age differences in their calculation of relative breast cancer risk. Concern has been expressed about this shortcoming especially since the groups

This is an emerging area of research and it is currently unclear if even the reported association will remain true.

examined did differ in the presence of several important breast cancer risk factors².

Is more evidence needed to establish this potential connection between antibiotic use and breast cancer risk?

An earlier article in *The Ribbon* discussed the five types of evidence needed to establish a cause-effect relationship between an exposure and occurrence of a disease (see *The Ribbon*, Volume 7 Number 4, 2002). The five types of evidence were: consistency of results; a reasonably high risk associated with the exposure; a dose relationship between level of exposure and disease; a biologically plausible relationship to cause; and finally a reasonable time between exposure and breast cancer occurrence. The evidence from these reports is evaluated in this light.

Currently there is consistency of results but in only two studies. These results could well be incorrect and their conclusions should still be considered preliminary. The results need to be verified in more studies. Such examinations will undoubtedly be conducted in the near future as existing cohort studies are likely to have information on antibiotic use by the members of their studies.

These studies reported about a doubling of risk. This would not be considered a very large increase in risk but could potentially affect many women. In response to this level of risk, some investigators have suggested that antibiotics may not be acting directly, but rather that antibiotic use is a measure of the women's immune function, as women with weaker immune systems would be likely to be prescribed more antibiotics. This is a very reasonable criticism as decreased immune function is related to cancer occurrence.

The JAMA study did examine and demonstrate a dose relationship between breast cancer risk and the level of exposure to antibiotics – risk progressively increased for groups of women with more prescriptions or days of antibiotic use. This provides an important piece of evidence, but here again these results need to be confirmed in other studies.

The results also need to be biologically plausible. There is ample evidence for biological plausibility. Studies have shown that antibiotics could increase breast cancer risk by several mechanisms, such as effects on the immune system, changes in the growth of cells and decreases in the absorption of beneficial chemicals from plants. But in addition,

there are studies which also support the ability of antibiotics to decrease breast cancer risk; antibiotics can increase estrogen elimination from the body, decrease the formation of estrogen, and have protective effects on cell growth.

Finally, the time of exposure has to be appropriate for cancer formation. The JAMA study also reported a sub-analysis of the women who had been in the program between 17 and 24 years, an appropriate time for cancer formation to be affected. They did not convey the actual risk values for this analysis but stated that an increase in risk was still observed. However, the level of risk was decreased and statistical significance was lost. Considerably more study is needed for each of the above types of evidence.

Should a woman's approach to antibiotic use change because of this report?

This is an emerging area of research and it is currently unclear if even the reported association will remain true. It is also uncertain if a relationship might be due to the antibiotics themselves or to medical conditions which would call for antibiotic treatment. At this point there is insufficient evidence to recommend changes in antibiotic use. 

References

1. Velicer CM, Heckbert SR, Lampe JW, Potter JD, Robertson CA, Taplin SH. Antibiotic use in relation to the risk of breast cancer. *Journal of the American Medical Association*. 2004;291(7):827-835.
2. Ness RB, Cauley JA, Velicer CM, et al. Antibiotics and breast cancer – what's the meaning of this? Antibiotic use in relation to the risk of breast cancer. *Journal of the American Medical Association*. 2004;291(7):880-881.
3. Knekt P, Adlercreutz H, Rissanen H, et al. Does antibacterial treatment for urinary tract infection contribute to the risk of breast cancer? *British Journal of Cancer*. 2000;82(5): 1107-1110.

enable them to serve on grant review panels and scientific advisory boards for major studies. For activists without prior experience with researchers, their feelings toward scientists changed from fear and anxiety to mutual respect and comfort. One woman who had worked on high-level government advisory panels recounted that:

"The thing that I came away with that was most surprising was how much the scientists and the MDs have come to value the activist perspective on these panels ... not only just putting a face on the statistics, but also ... they appreciate that... you ask the questions: why is this relevant, who cares?"

This quote exemplifies a theme we found running throughout interviews regarding the alliances, that it was a transformative experience for both parties in which they learned to appreciate the very different perspective of the other group. This occurred despite initial reservations.

We might expect scientists to worry that their legitimacy would be threatened if they worked with laypeople. Scientists involved in alliances in this movement described some initial fear, but general mutual respect between themselves and activists. They often greatly appreciated the input activists supplied, in addition to their efforts that brought research projects into existence. Of course, this may be a biased sample of scientists who were previously open to activist involvement in research, even though they came from a wide diversity of backgrounds and experience.

Apprehension and prejudice on the part of both activists and scientists against the other group were the most serious obstacles to alliances. Still, most laywomen felt that they were respected and that their work was worthwhile and transformative. These initial fears and prejudices were verbalized by one activist whose experience demonstrated how this transformation took place:

"I think there is a respect for bright people and I think the assumption often is that activists are going to be hysterical women. And I think once most scientists realize that we're not hysterical women, they find themselves, you know, intrigued. And they might come to the table with a lot of prejudices and worries but I have rarely seen it continue to be a problem."

Activist involvement in science pushes scientists to examine why they ask certain questions and not others, why they use certain methodologies, and more importantly, pushes them to examine how their research affects women with breast cancer. An activist provided an emblematic example of such questioning: a lay member of a review panel listened to a scientist give an extremely high score to a proposal simply on the basis of excellent methodology. When the laywoman pressed the scientist on the actual relevance of the project, the scientist realized the error and revised the score downward. Alliances between scientists and laypeople are valuable not only for environmental breast cancer activists, but also for many other arenas of environmental health. Citizen/science alliances represent one of the most significant legacies of this movement.

Conclusions

The environmental breast cancer movement's multilevel successes include the significant amount of public awareness that has been generated, the amount of research that has been performed, the dialogue that has been created in the scientific community, and the development of citizen/science alliances. Our examination of the movement provides important lessons about the character and components of health social movements, and we, expect, other social movements as well.

As we have shown, this social movement developed as a boundary movement that crossed the lines of a number of other social movements. While local culture variations make each locale of the movement somewhat different, we believe that there are sufficient similarities to justify viewing this as a coherent national movement. It exemplifies social movement activity at the intersection of health and the environment, which is quite possibly the largest new arena of social movements,

encompassing activism around lead poisoning, asthma, toxic wastes, nuclear power, food additives, biotechnology/genetically modified organisms, toxics reduction, and the precautionary principle (Brown *et al.*, 2002). This case study leads us to predict that future social movements, especially involving health and environment issues, will arise in similar boundary-crossing fashion. Social movements have an enormous range of facets: political challenges to governmental authority, scientific challenges to medicine and science, organizational challenges to health charities and related organizations, contention for power and authority among various

Citizen/science alliances represent one of the most significant legacies of this movement.

organizations within a movement, cultural manifestations, and activities to increase public awareness. The environmental breast cancer movement exemplifies these multiple facets, and shows how they are interlinked. Most prior social movement theory does not provide for such a perspective, so we view this as a new way to examine social movements.

Boundary movements such as the environmental breast cancer movement are centrally concerned with democratic participation in science and in social policy involving that science. The movement shows the strength of the abilities of ordinary citizens in this movement to learn science, to demand a seat at the table for reviewing research proposals, to collaborate in research enterprises, and to press for broad extensions of citizens' right to participate in all aspects of society. Thus, the environmental breast cancer movement continues in a long line of social movements that seek to expand democracy, but does it in a qualitatively new fashion that holds great promise for empowering citizens, while at the same time helping to improve scientific practice, improve the health of the public, and reshape the priorities of science and medicine. 

This research is supported by grants to the first author from the Brown University Graduate School and Department of Sociology, and to the second author from the Robert Wood Johnson Foundation's Investigator Awards in Health Policy Research Program (Grant #036273), the National Science Foundation Program in Social Dimensions of Engineering, Science, and Technology (Grant # SES-9975518), and the Brown University Salomon Faculty Research Award Program. We thank Rebecca Gasior, Meadow Linder, Theo Luebke, Josh Mandelbaum, Brian Mayer, Rachel Morello-Frosch, and Pamela Webster for their collaboration in the larger project from which this work derives, and their contributions to thinking about this paper. We thank Elizabeth Cooksey and Sally Zierler for helpful readings of the manuscript. We are grateful to all the organizations and activists who facilitated our research, and especially to the scientists and staff of Silent Spring Institute for permitting us access to their work. We thank the Eastern Sociological Society for permission to print this edited version of "The Personal Is Scientific, The Scientific Is Political: The Public Paradigm of the Environmental Breast Cancer Movement," published in Sociological Forum, 2003 18:545-57.

References

- American Cancer Society**
2002 Cancer facts & figures 2002.
- Aschengrau, A., D. Ozonoff, R. Vezina, T. Heeren, and Y. Zhang**
1996 "Cancer risk and residential proximity to cranberry bog cultivation in Massachusetts." *American Journal of Public Health* 86:1289-1296.
- Brenner, Barbara**
2000 "The breast cancer epidemic." Presentation at American Public Health Association Conference, Boston, MA. November 13, 2000.
- Brown, Phil, Stephen Zavestoski, Sabrina McCormick, Brian Mayer, Rachel Morello-Frosch, and Rebecca Gasior**
2002 "Health social movements: Uncharted territory in social movement research." Presentation at ASA Collective Behavior and Social Movements Section conference August 15, 2002, Notre Dame IN.
- Davis, Devra Lee, and H. Leon Bradlow**
1995 "Can environmental estrogens cause breast cancer?" *Scientific American* October:166-172.
- Dickersin, Kay, Lundy Braun, Margaret Mead, Robert Millikan, Anna Wu, Jennifer Pietenpol, Susan Troyan, Benjamin Anderson, and Frances Visco**
2001 "Development and implementation of a science training course for breast cancer activists: Project LEAD (leadership, education and advocacy development)." *Health Expectations* 4:213-220.
- Dorgan J., John Brock, Nathaniel Rothman, Larry Needham, and Rosetta Miller**
1999 "Serum organochlorine pesticides and PCBs and breast cancer risk: results from a prospective analysis." *Cancer Causes and Control* 10: 1-11.
- Epstein, Steven**
1998 *Impure Science: AIDS, Activism, and the Politics of Knowledge*. Berkeley: University of California Press.
- Guttes, S., K. Failing, K. Neumann, J. Kleinstein, S. Georgii, and H. Brunn**
1998 "Chlororganic pesticides and polychlorinated biphenyls in breast tissue of women with benign and malignant breast disease." *Archives of Environmental Contamination and Toxicology* 35(1): 140-147.
- Hoyer, A., Torben Jorgensen, Philippe Grandjean, and Helle Boggild Hartvig**
1999 "Repeated measures of organochlorine exposure and breast cancer risk." *Cancer Causes and Control* 11:177-184.
- Hoyer, A.P., T. Jorgensen, J.W. Brock, and P. Grandjean**
2000 "Organochlorine exposure and breast cancer survival." *Journal of Clinical Epidemiology* 53(3):323-30.
- Hunter, David J., Susan Hankinson, Francine Laden, Graham Colditz, JoAnne Manson, Walter Willett, Frank Speizer, and Mary S. Wolff**
1997 "Plasma organochlorine levels and the risk of breast cancer." *The New England Journal of Medicine* 337:1253-1258.

References continued on page 11

Activist Update: The History of the Breast Cancer Mapping Project

By Lorraine Pace, Founder and Co-President of Breast Cancer Help, Inc.

WHEN I WAS DIAGNOSED WITH BREAST CANCER IN 1992, I FOUND OUT THAT 20 OTHER WOMEN IN MY COMMUNITY WERE ALSO DIAGNOSED WITH BREAST CANCER. I WAS DETERMINED TO FIND OUT IF I WAS LIVING IN A HIGH INCIDENCE AREA, SO I CONTACTED THE SUFFOLK COUNTY DEPARTMENT OF HEALTH.

After repeated calls to the Health Department, they informed me that at that time Port Jefferson was a higher risk area than West Islip. However, at that time cancer information reported from New York hospitals and submitted to the Department of Health was done by post cards that sat in boxes for approximately five years before being documented.

It was for this reason that I began the West Islip Breast Cancer Mapping Project in 1992 that pinpointed breast cancer clusters. This original mapping project, which spearheaded the breast cancer environmental movement, has now spread to other parts of New York, the United States and abroad. These mapping projects also helped prompt the Long Island Breast Cancer Study Project, a five year study, funded and coordinated by the National Cancer Institute.

The first 50 years of my life were filled with family, a career in real estate, and a return to college where I earned a bachelor and masters degree. I am a mother of three, but nothing in those years prepared me for my 50th year in 1992: the year that I discovered that the lump I had been feeling in my left breast for many years was what I had feared all along – it was cancer and had spread to my lymph nodes.

That is when I became an activist. I never smoked in my life and I am only an occasional social drinker. I was not on hormone replacement therapy and was on birth control pills for only two months. I had all my children before the age of 30. I was in excellent health, had good eating habits, and exercised regularly. Neither one of my grandmothers or my mother had breast cancer. I did everything that I was supposed to do for early detection, including having regular mammograms since my early 30s. I knew there had to be another reason why I developed breast cancer.

A while after I was diagnosed with breast cancer, it struck me that 20 other women I knew had also been diagnosed. After a great deal of thought, the one thing I could see that we had in common was that most of us lived on dead-end streets. I started to think about what

this could mean.

Our community has lovely fresh air and water views. The only thing that was odd about this environment was that occasionally my tap water was rusty. I began to wonder if possibly, the metals that made the water rusty could have anything to do with the breast cancer rate in my neighborhood and the rest of Long Island. I read that the Center for Disease Control was to come to Long Island. I testified before them in 1992, less than two months after being diagnosed with breast cancer. I showed my rusty water and asked them if there was any connection.

Once I began to suspect the culprit might be the water, I looked around at other communities and at other environmental factors that could be involved. I found that New York City has a much lower rate of breast cancer than Long Island. Yet they are so close to us—just a few miles. I had to wonder, was it because they get their water from upstate reservoirs? Or that they don't have lawns that they obsessively fertilize, dumping every kind of chemical into the underground aquifer that is our sole source of water? Or, is it because their wires are buried underground instead of overhead like they are in parts of the suburbs?

When there appeared to be no answers to my questions, I asked my oncologist, Dr. Michael Feinstein, to help me prove a theory I had about dead-end water mains. My concern was that if you lived on a dead-end street the water did not circulate as well as if you lived in the middle of the block and you were exposed to more contaminants. He offered his help to see if this theory could be proved. On his days off we met with former Suffolk County Health Commissioner Dr. Mary Hibberd and the head of the Suffolk County Water Authority, Michael LoGrande, to develop a survey. Through our contacts with Good Samaritan hospital, I was able to contact Lou Grasso, editor of Suffolk Life Newspapers, and Dave Wilmott, publisher of Suffolk Life. They in turn printed the survey on their front page which is how the breast cancer mapping originated.

REFERENCES FOR THE ENVIRONMENTAL BREAST CANCER MOVEMENT *continued from page 9*

My radiation oncologist, Dr. Allen G. Meek, encouraged me to pursue the mapping project. With the help of Maria Diorio and many other volunteers from the neighborhood we put the responses from the survey onto a map. This was done from my dining room table every day for 18 months. The map showed clusters of breast cancer with definite patterns of concentration in certain areas. After the mapping was completed we received a 69% response from the community, and that was due to efforts by friends, neighbors and volunteers. This was the first breast cancer related geographic information system ever completed. NJ Burkett of Channel 7 Eyewitness News did a series on breast cancer mapping and was awarded the FOLIO Award for his coverage. Suffolk Life Newspaper also received a FOLIO Award for their newspaper coverage.

In 1992, I started the West Islip Breast Cancer Coalition. Meanwhile, I received calls from women in Huntington, Great Neck, Babylon, Southampton, Brentwood, Islip and Brookhaven asking for assistance on how to do mapping in their towns. New York State Senators Owen Johnson and Caesar Trunzo gave a grant to the West Islip Breast Cancer Coalition to study the map, and Dr. Roger Grimson, a biostatistician of Stony Brook University, did the scientific analysis.

I could not have accomplished all of this without the help and support of my community, especially my neighbors in West Islip. Without Good Samaritan Hospital lending their name to the project, we couldn't have received such an enormous response to the surveys. I would also like to thank my family for their help and support, including my husband for forming the 501(c)3 pro bono, and my daughter-in-law who took her time to answer all of the calls from the survey while she was at work in my son's real estate office.

After leaving the West Islip Breast Cancer Coalition in 1993 I started Breast Cancer Help, Inc. in 1994. I am currently co-president of this organization which I formed to help find the cause(s) of and a cure for breast cancer. Breast Cancer Help is a not-for-profit grass roots organization with a focus on action and advocacy to eradicate breast cancer. In 1994, we were the only breast cancer organization to have men on our board with men acting as co-president, board chairman, treasurer, secretary, and general counsel. ♀

For more information about Breast Cancer Help, Inc. please call (631) 661-7223 or visit www.breastcancerhelpinc.org

Kant, A.K., A. Schatzkin, B.I.Graubard, and C. Schairer
2000 "A prospective study of diet quality and mortality in women." *Journal of the American Medical Association* 283(16):2109-2115.

Krimsky, Sheldon
2000 Hormonal Chaos: The Scientific and Social Origins of the Endocrine Disrupter Hypothesis. Baltimore: Johns Hopkins University Press.

Lichtenstein, P., N. Holm, PK Verkasalo, A Iliadou, J. Kaprio, M. Koskenvuo, E. Pukkala, A. Skytthe, and K. Hemminki
2000 "Environmental and heritable factors in the causation of cancer—analyses of cohorts of twins from Sweden, Denmark, and Finland." *New England Journal of Medicine*: 343:78-85, July 13, 2000

Raffensperger, Carolyn, and Joel Tickner (eds.)
1999 Protecting Public Health and the Environment: Implementing the Precautionary Principle. Washington, DC: Island Press

Reiss, Joan Reinhardt, and Andrea Ravinett Martin
2000 "Breast cancer 2000: An update on the facts, figures and issues." San Francisco: The Breast Cancer Fund.

Robbins, Anthony S., Sonia Brescianni, and Jennifer Kelsey
1997 "Regional differences in known risk factors and the higher incidence of breast cancer in San Francisco." *Journal of the National Cancer Institute* 89: 960-964.

Ruzek, Sheryl Burt, Virginia L. Olesen, and Adele Clarke (eds.)
1997 Women's Health: Complexities and Differences. Columbus, OH: Ohio State University Press.

Star, Susan Leigh, and James R. Griesemer
1989 "Institutional ecology, 'translations' and boundary objects: Amateurs and professionals in Berkeley's Museum of Vertebrate Zoology, 1907-39." *Social Studies of Science* 19:1907-1939.

Thompson, H.J.
1992 "Effect of amount and type of exercise on experimentally induced breast cancer." *Advances In Experimental Medicine and Biology* 322:61-71.

Weisman, Carol S.
1998 Women's Health Care : Activist Traditions and Institutional Change. Baltimore: Johns Hopkins University Press.

West, Dee W., Sally Glaser, and Angela Witt Prehn
1998 Status of Breast Cancer Research in the San Francisco Bay Area. Northern California Cancer Center.

Wolff, Mary S., Paolo G. Toniolo, Eric W. Lee, Marilyn Rivera, and Neil Dublin
1993 "Blood levels of organochlorine residues and risk of breast cancer." *Journal of the National Cancer Institute* 85:648-652.

The Ribbon is published by the Cornell Program on Breast Cancer and Environmental Risk Factors. Funding provided by the New York State Departments of Health and Environmental Conservation.

Editor

Carmi Orenstein, M.P.H.,
Assistant Director

Design

West Hill Graphics,
Ithaca, NY

Visit our web site at:

<http://envirocancer.cornell.edu>

PLEASE JOIN US...

BCERF Regional Cancer and Environment Forum to take place on the Cornell Campus in Ithaca

Hagen Room

**College of Veterinary Medicine
Cornell Campus, Ithaca**

Friday, June 4, 2004

10:00am - 3:00pm

FEATURED TOPICS AND SPEAKERS WILL INCLUDE:

Mammographic Density and the Incidence of Breast Cancer: A Modifiable Example of Gene-Environment Interaction

Dr. Norman Boyd, Head, Division of Epidemiology, Statistics and Behavioural Research, Ontario Cancer Institute

Obesity, Environment and Breast Cancer Risk

Dr. Barbour Warren, BCERF

Breast Cancer Advocacy: History and Context

Bob Riter, Associate Director, Ithaca Breast Cancer Alliance

Folate, Cancer, Genetic Variation and the Food Supply

Dr. Patrick Stover, Division of Nutritional Sciences, Cornell University

Opportunities for discussion with all presenters, plus time to make announcements, provide updates, and interact with other participants. We hope you can join us!

For more information or to RSVP, please call or email Carmi at 607.272.3959 or cso1@cornell.edu



Cornell University
Program on Breast Cancer and Environmental Risk Factors
Box 31, College of Veterinary Medicine
Cornell University
Ithaca, NY 14853-6401

Phone: (607) 254-2893

Email: breastcancer@cornell.edu