



Grassroots Breast Cancer Advocacy and the Environment

A Report on Interviews with Grassroots Leaders

Executive Summary

In 2004, Silent Spring Institute launched a program of outreach among leaders of grassroots breast cancer organizations. Our aim was to interview these leaders to learn about their current priorities and, in particular, how they view environmental issues in relation to breast cancer advocacy.

We began by conducting interviews with 56 leaders in the US and Canada. Results of the interviews showed a substantial interest in the environment among leaders of grassroots organizations.

- 45% said questions about environmental factors had come up for their organization.
- 70-82% rated as “very important” research about workplace chemicals, air pollution, pesticides, household chemicals, drinking water, and endocrine disrupting compounds.
- On average, grassroots leaders said 47% of the breast cancer research dollar should be spent on environmental research.
- 23% are actively addressing local environmental issues.

Introduction

About 250,000 US women will learn this year that they have breast cancer; and breast cancer risk continues to climb in the US and worldwide, with the greatest increases in previously low-risk developing nations and US immigrant populations. Most breast cancer risk remains unexplained by established risk factors, and scientists estimate that only one fourth of the risk is attributable to inherited genes.

The statistics are grim, but scientists see real hope for the discovery of preventable causes of breast cancer. One area of inquiry is the compelling evidence from wildlife and laboratory studies that exposure to certain types of chemicals may increase risk. If these findings prove true for humans, we may be able to limit exposures and prevent the onset of this deadly disease. Yet only a small fraction of breast cancer dollars are designated for finding

causes we can prevent; and a still smaller fraction addresses possible environmental factors, despite evidence indicating that such exposures may be both causative and preventable.

An increasing number of breast cancer organizations are focusing attention on environmental research and precautionary public health policies. The largest and most influential breast cancer advocacy organizations provide relatively few resources on environmental issues, though; and this contrast led us to develop a program to identify grassroots breast cancer advocacy organizations and interview their leaders about priorities and needs. Information from this survey will help shape Silent Spring Institute's research and outreach plans, and we hope it will spur additional national interest in environmental research as well.

About Silent Spring Institute

Founded in 1994 by leaders in the Massachusetts Breast Cancer Coalition (MBCC), Silent Spring Institute is an alliance of scientists and activists dedicated to studying the links between the environment and women's health, especially breast cancer. Our goal is to build the knowledge base for prevention. Research teams include Silent Spring Institute scientists and co-investigators at Brown University, Harvard University, the US Centers for Disease Control, and elsewhere. We have trained students from more than a dozen colleges and universities. The Institute's first and largest study is the Cape Cod Breast Cancer and Environment Study, and we have become leaders in identifying environmental pollutants in homes.

Methods

We identified 125 grassroots breast cancer organizations through systematic internet searches and personal connections in breast cancer advocacy networks. We focused on contacting independent organizations with less emphasis on organizations that function as chapters of national organizations but included independent organizations that belong to larger coalitions.

Silent Spring Institute's Outreach Coordinator Cheryl Osimo telephoned all 125 identified organizations and left up to three messages as necessary. She successfully interviewed leaders of 56 organizations. Although there were no refusals, we were unable to contact 69 organizations using this method. We are continuing our efforts to contact these 69 organizations and to identify new organizations for inclusion in the study.

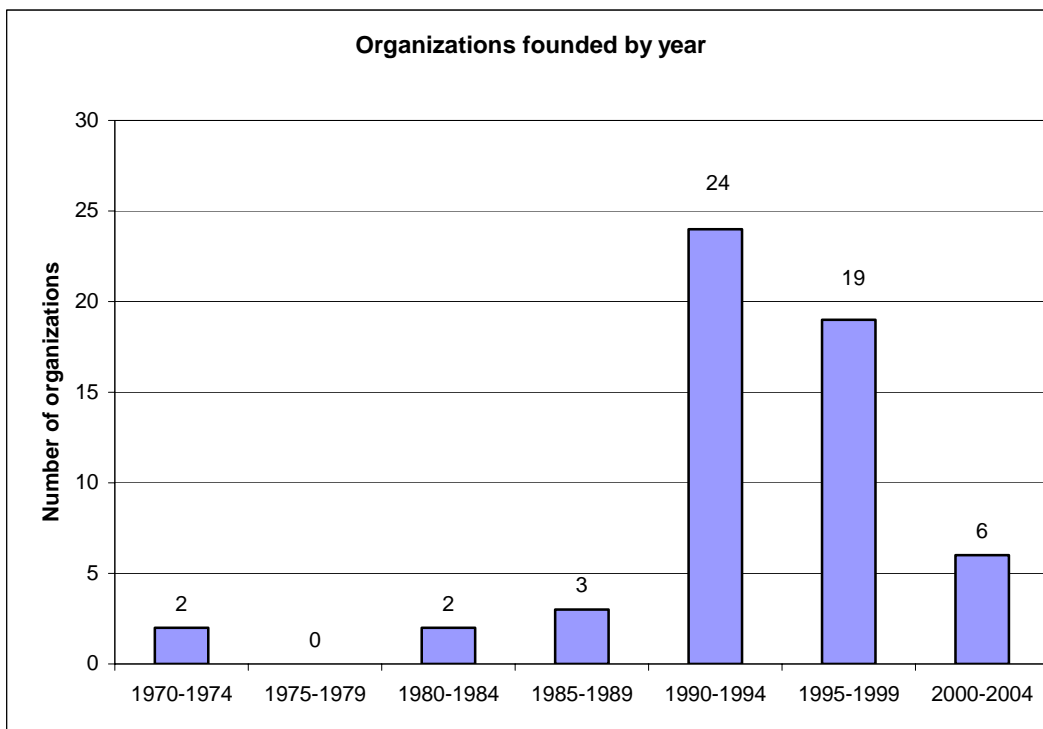
Interviews included both structured questions and open-ended opportunities for leaders to share their thoughts. Conversations typically lasted between 30 and 60 minutes. The interview covered organizational history, mission, priorities, attitudes toward environmental issues, and information needs in this area.

Results and Comments

Characteristics of Grassroots Breast Cancer Advocacy Organizations

Silent Spring Institute interviewed leaders of 56 organizations in 27 states and 2 Canadian provinces. The median number of people involved with each organization was 225.

- Breast cancer advocacy has become such a powerful constituency that it is hard to remember that this social movement is young and still emerging. The average founding year for organizations in the study was 1994 (see graph). The oldest organization, Breast Cancer Resource Center of Princeton NJ, was founded in 1974. For reference, the National Breast Cancer Coalition (NBCC) was founded in 1991.



- Affiliations with NBCC were prevalent in the group, with 21 organizations founded by NBCC affiliated women, identifying with NBCC priorities, and/or working directly with NBCC.
- Many of the organizations have a presence on the Internet. Forty-one have websites that list events, information, and web links. In addition, 39 organizations distribute information through printed newsletters.

The surveyed organizations participate in a wide variety of activities including research and education, outreach, and services. Examples of the type of projects in which they are engaged follow:

Research and Education

- working with research organizations and universities on policy and research
- mapping breast cancer incidence in neighborhoods
- maintaining educational materials or a library
- creating resource guides

Outreach

- organizing speakers, workshops, conferences, and booths at health fairs
- creating websites
- developing awareness events (Bells for Remembrance: Breast Health Connection of Georgia, Wall of Hope: Breast Cancer Alliance of Greater Cincinnati)
- fundraising

Services

- providing training on diversity issues
- sponsoring exercise and recovery programs
- offering financial assistance to women diagnosed with breast cancer
- creating mentoring programs
- facilitating support groups
- lobbying
- starting special focus groups: for minorities, gays and lesbians, young survivors
- advocating for the needs of underserved women

Not surprisingly, leaders' priorities fell into the same general categories of research and education, outreach and services. Examples of where they plan to focus their energies in the future are as follows:

Research and Education

- update resource materials
- develop special programs
- review policy positions, such as whether to create a mammography registry

Outreach

- plan a conference
- increase membership
- expand outreach to specific populations (e.g., Asian women)
- expand legislative grassroots base
- partner with other organizations such as the Susan G. Komen Breast Cancer Foundation, the Avon Breast Cancer Crusade, the National Institutes of Health

Services

- lobby
- help underserved women (free mammograms, wigs, treatment)
- provide patient services
- expand into all areas of lesbian health

Other

- support NBCC priorities
- secure funding
- fill gaps caused by the death of leaders
- hire new personnel
- fundraise

Environmental Factors and Breast Cancer Prevention

Many breast cancer leaders expressed interest in environmental factors but did not currently consider them part of their organization's scope. One woman stated, "We have to focus on screening and access to care, because there are so many women that don't have access to care. After they are screened and diagnosed, if they don't have access to care then they die. So we don't have time for the environment."

Leaders also voiced stress from lack of resources and repeated loss. One group reported that of their 18 founders, all but four have died. The immediacy of the illness and pressing need to

create services, deplete organizations' ability to look for causes and ways to prevent this disease. However, in response to the changing concerns of their members, some organizations are integrating environmental activities into their programs. A director of an on-line information resource stated, "Most people who go to our site are in panic mode. After cure or remission they kick into environmental mode."

"Most people who go to our [web] site are in panic mode. After cure or remission they kick into environmental mode."

While only five organizations used the words "cause" or "prevention" in their mission statements, 25 (45%) stated that environmental issues had come up for their organizations and 13 (23%) are actively addressing environmental issues within their communities.

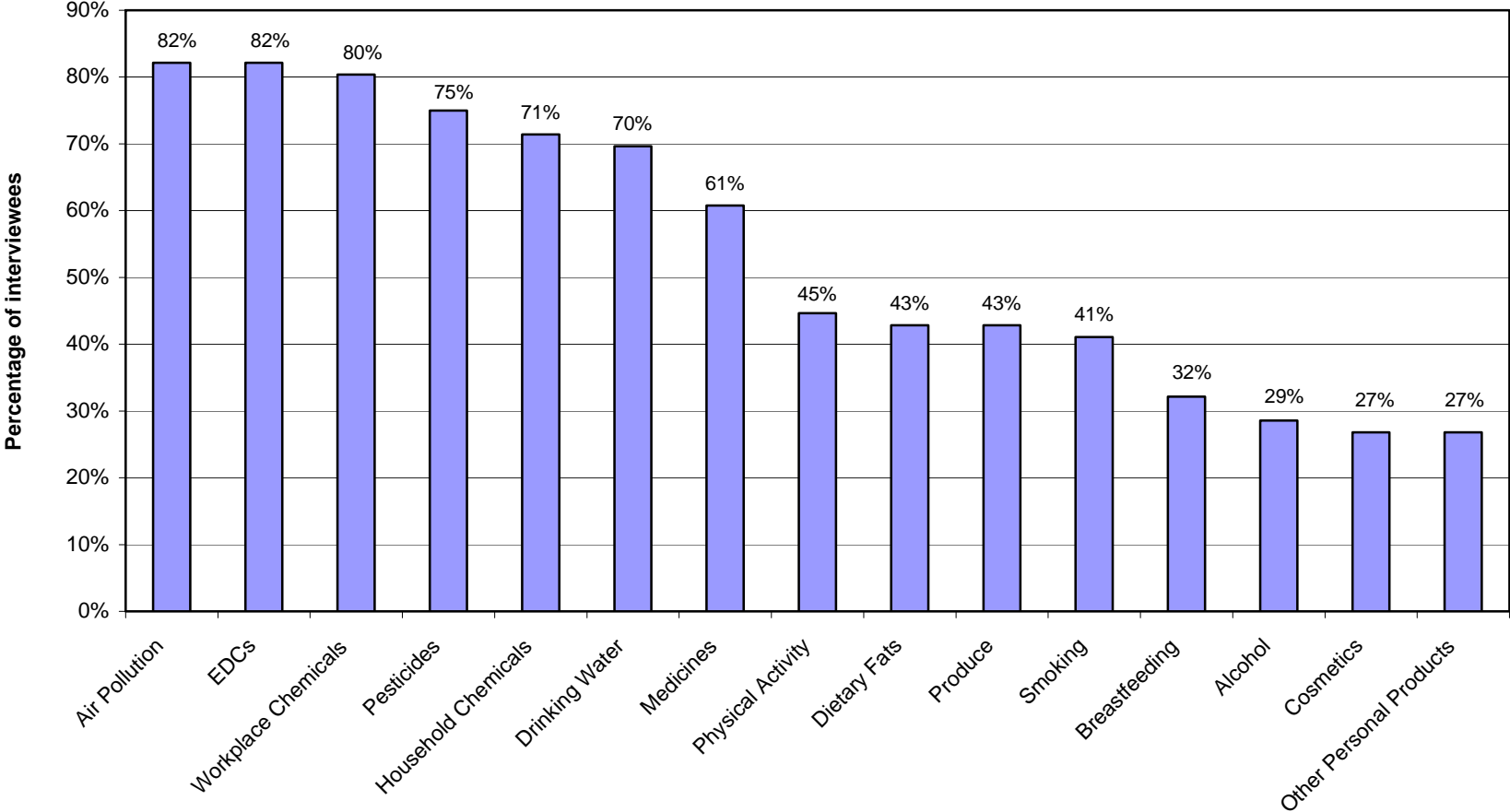
Leaders mentioned specific environmental factors they would like to see researched further: hormones in meat and poultry, deodorant, viruses, nuclear waste, school bus fumes, solvents, x-rays, power lines, cell phones, and fertility drugs. Others stressed the importance of studying the effects of multiple factors acting simultaneously and the interplay of genetics and the environment.

Organizations are also becoming active on local environmental issues.

- In Canada, women are concerned about exposures from chemical factories near Detroit.
- In southwest Missouri, women are questioning the role environmental exposures may be playing in an increase in diagnoses in women in their early twenties.
- In the Hudson Valley, women are drawing attention to exposures from chemicals sprayed on the region's cornfields and apple orchards and to the everyday and often-unacknowledged exposures from personal care products and other consumer items.
- In Maine, families who have lived near paper and other mills for generations are concerned that pockets of cancers in this region may be related to their exposures from the mills.

In addition to local environmental issues, we asked about the importance of studying a series of possible causes of breast cancer. About 70 to 82% ranked as "very important" research about workplace chemicals, air pollution, pesticides, household chemicals, drinking water, and endocrine disrupting compounds (EDCs), which are chemicals that mimic estrogen or otherwise disrupt hormones. In comparison, survey respondents rated diet, a research area that receives substantial funding, "very important" only 43% of the time. The graph on the following page depicts the number of respondents who chose "very important" as their answer. (Answer choices were "very important," "somewhat important," "not very important," "not at all important," and "no answer/don't know.")

**How important do you think it is to research these possible breast cancer risk factors?
Answer: "very important"**



Access to Information and Resource Allocation

With a growing interest in possible environmental links to breast cancer, many grassroots breast cancer organizations are finding that their members are turning to them for credible information. To meet this growing demand, these groups are sponsoring conferences

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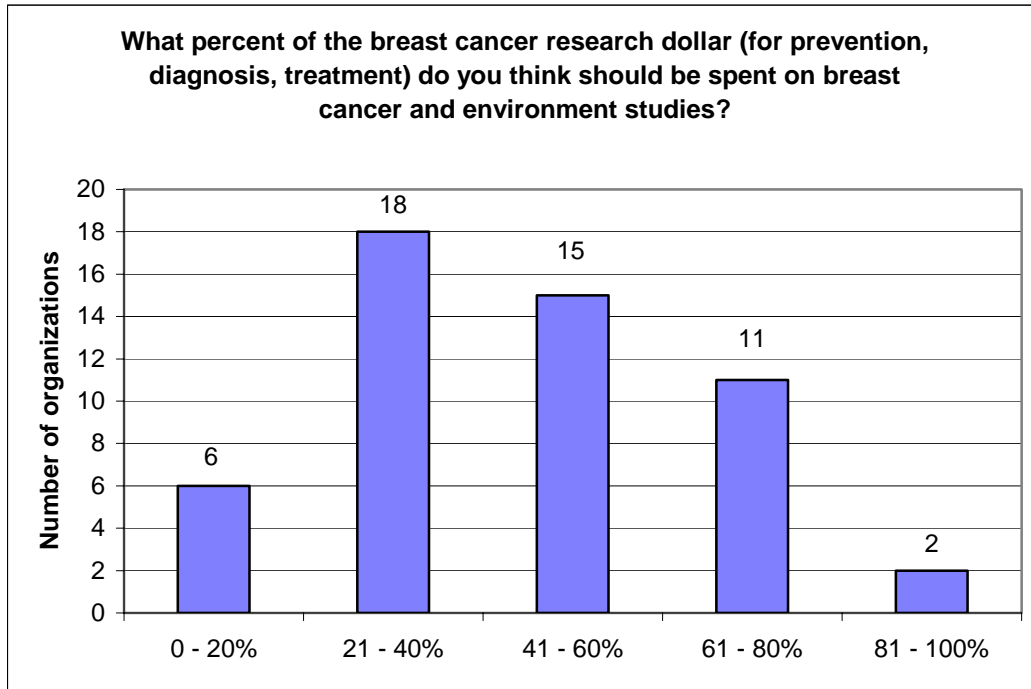
on the environment, pursuing local pesticide bans, creating a website for pesticide free lawns for children, participating in biomonitoring research, supporting the precautionary principle, and creating subcommittees on the environment.

In this context, it is especially gratifying to hear leaders expressing a sense of support, relief, and gratitude from knowing that Silent Spring Institute is pursuing

environmental studies. One leader said, “I am thrilled that there is an organization that is finally looking at the environmental link to breast cancer.”

Of those surveyed, nearly half (48%) had heard of Silent Spring Institute, and almost all (93%) were interested in receiving articles, appropriate for inclusion in a newsletter, on developments in scientific research on breast cancer and the environment.

We also asked survey participants what percentage of breast cancer research should focus on environmental links. These leaders stated clearly and consistently that more funding should go to environmental research. On average, they said that 47% of breast cancer funding should be dedicated to environmental studies compared to the less than 5% that is currently allocated. The results show a sharp divergence between the leaders’ priorities and the current funding reality. The following graph shows the distribution of replies.



Summary and Conclusion

Interviews with 56 leaders of grassroots breast cancer advocacy organizations in the US and Canada indicate that research priorities would be dramatically refocused on environmental issues if these leaders were in charge. On average, survey participants said 47% of the breast cancer research dollar should be spent on environmental studies. Specific areas on which leaders would like more research include endocrine disrupting compounds, workplace chemicals, air pollution, pesticides, household chemicals, and drinking water, with 70-82% of leaders rating these areas as “very important” compared with 43% for diet studies.

Our interviews indicate that as the grassroots organizations have matured, their focus has shifted. Although only a small minority of the organizations included breast cancer etiology, prevention, or environment in their mission statement, nearly half report that now, environment is an issue for their group, and about one fourth are actively working on environmental concerns.

Although the methodology we used to identify the participating organizations was more likely to identify larger and more-established groups, we have no reason to suspect the selection methods would bias results to a particular point of view. The data in this survey provide much-needed information on the priorities of grassroots breast cancer organizations and demonstrate that there is a substantial constituency with a strong interest in being more informed and active on environmental issues.

Next Steps

Silent Spring Institute is dedicated to bringing activists and scientists together in partnerships to identify links between the environment and women's health. We therefore plan to continue our outreach with the organizations that participated in this survey and hope to expand our efforts through additional interviews with grassroots leaders nationally. This work enables the Institute to monitor the changing concerns and needs of grassroots leaders so we can refine our own research and pursue the questions women want answered. It also provides national leaders and decision-makers a database of grassroots organizations' priorities, so that they can make informed decisions about resource allocation.

In addition to participating in the survey, there are many ways grassroots leaders can join us in this effort.

- Identify additional breast cancer organizations we should contact to interview.
- Let us know if you would like to receive updates on current scientific developments in breast cancer and environment research.
- Share your concerns about increasing funding for environmental research with the national breast cancer advocacy organizations and push for its inclusion on their action agendas.
- Educate yourself and your members about research into possible preventable causes of breast cancer.
- Let Silent Spring Institute know if there are other ways we can support your efforts.

Silent Spring Institute is a forum where advocacy and scientific concerns are shared to create a common agenda. Your active participation helps us realize the vision of the inspiring women and men who founded this unique organization.

For more information about Silent Spring Institute's research on women's health and the environment, please visit our web site at www.SilentSpring.org

Acknowledgements

We are grateful to all the leaders who took the time to speak with us as part of this survey and look forward to working more with this motivated and impassioned group of people. We thank the Beldon Fund for its generous support of this project. Outreach Coordinator Cheryl Osimo conducted the interviews. Researcher Kathleen Attfield conducted the data analysis and prepared this report with input from Ruth Polk, consultant to Silent Spring Institute.