

We want to make our science responsive to the American people. I don't know how we find out what the American people want without going out and talking to them. — *Dr. Kenneth Olden*

The October weather can still feel like summer in Northern California, and on October 8, 2002 Marin County was just a few degrees shy of record-breaking heat. The air in one packed meeting room was warm and stuffy -- but also charged with excitement. Two hundred people had come to be part of a Town Hall Meeting convened by Kenneth Olden, PhD, director of the National Institute of Environmental Health Studies (NIEHS).

His previous Meetings around the country had discussed topics like health disparities and heavy metal exposure among children. Fittingly for Marin County, this one was about breast cancer. Marin residents were concerned -- understandably, when the local paper was publishing articles like this one:

Breast cancer in Marin County leaped a stunning 20 percent in one year, solidifying the region's status as the breast cancer capital of the country, health officials said yesterday....The Bay Area as a whole has the highest rate in the world, according to the Northern California Cancer Center, which conducted the study. ([San Francisco Chronicle, Jan 17 2002](#))

The Town Hall was hosted by Zero Breast Cancer, (then known as Marin Breast Cancer Watch) and dozens of its supporters were eager to speak. Dr Olden listened closely throughout the two day event and into the evening. And then, in order to discover how chemical, physical, biological, and social factors in the environment work together with genetic factors to cause breast cancer, he announced the imminent release of a Request for Applications for Breast Cancer and the Environment Research Centers (BCERCs).

## The origins of the BCERC

During the 1990s high incidence made breast cancer an urgent public health priority. Although the premise had its detractors, Dr Olden believed in the public health value of the search for environmental links to breast cancer. The BCERCs were among the many large-scale scientific undertakings he championed while director of the NIEHS.

A timely combination of social and scientific developments set the stage for the Centers' creation. Although political will and funding lagged for research into environmental links to breast cancer, the years leading up to the BCERC saw the convergence of relevant factors such as

- Growing feminist, patient advocacy and environmental justice movements
- Breakthrough science, which was uncovering tantalizing data about carcinogenesis, environment and relationships between the two

This paper explores the convergence and one of its significant outcomes, the creating of the BCERC.

### **Feminism and patient advocacy**

The late 20<sup>th</sup> Century "second wave" of US feminism helped breast cancer come out of the shadows, supporting the public disclosure of diagnoses by Betty Ford and other high

profile women. In the 1980s still greater respect was accorded to women's health, and concerns about potential environmental risk factors could no longer be dismissed by characterizing them as "emotional" because they were raised by women, as some researchers tried to do.

In 1986 the Women's Cancer Resource Center emerged in Berkeley California, likely the first feminist cancer organization in the US. The founders were breast cancer patients who hoped that solidarity with others would help them be informed healthcare consumers and cancer survivors.

### **The Environmental Justice Movement**

"Ethical, balanced and responsible uses of land and renewable resources in the interest of a sustainable planet for humans and other living things" and ... "public policy... free from any form of discrimination or bias" are founding principles of the Environmental Justice Movement. By most accounts the Movement began in the 1970s ([Environmental Justice Resource Center](#)) and by 1991 the Movement could summon 650 activists from around the world to a four day conference.

Environmental justice campaigns often began because of concern about unexplained "clusters" of disease and a dearth of research as to why so much suffering would be centered in a particular geographic area. After one such observation the New York State Health Department conducted a study in 1983 to examine breast cancer risk on Long Island. The Huntington Breast Cancer Action Coalition, later to participate in the BCERC Working Group, traces its origin to that period.

### **Lab and population science vs cancer**

The premise that environmental toxins could be linked somehow with cancer had been accepted since the early twentieth century ([Cantor, 2007](#)) and animal studies implicating external catalysts for carcinogenesis were numerous and damning. A [1961 study](#) by Nobel Prize winner Charles Huggins was an early example: he showed that administration of polycyclic aromatic hydrocarbons (PAHs) to 50-day-old female rats produced nearly a 100 percent incidence of mammary cancer. By 1995, the list of suspected risk factors for breast cancer included organochlorine pesticides (DDT/DDE and PCBs), electromagnetic fields, by-products of charbroiling food (heterocyclic amines), phytoestrogens from soy products, and breast implants. ([EHP, 1995](#))

Although it wasn't until 2003 that the human genome was cracked, scientists during the 1990s enjoyed an explosion in the rate of discovery in molecular biology and genetics. The growing field of molecular epidemiology sought to identify gene alterations that could affect one's chance of developing cancer after an environmental exposure to a carcinogen or catalyst. In 1997 the NCI created the Division of Cancer Control and Population Sciences (DCCPS) with the operating hypothesis that both genetic and environmental factors contribute to the development of cancer. Personally modifiable, or "lifestyle" factors such as diet continued to be of high interest -- according to a 1997 DCCPS report "data show that lifestyle and environmental influences are responsible for a majority of the cancer burden."

### **Political will: activists and scientists get better acquainted**

Focus on lifestyle factors was unacceptable to many advocates, who believed it shifted an inappropriate burden of responsibility to individuals. Advocates' efforts to increase and influence research into grew steadily during the 1990s. They proposed dramatically different types of relationships between their groups and the scientific establishment. Breast cancer prevention was their ambitious, if not radical, goal.

Frances Visco became the first president of the National Breast Cancer Coalition (NBCC) in 1991. NBCC members acquired a reputation for being thoroughly versed in the latest data on cancer as well as intimately acquainted with the needs of breast cancer patients. "We consider ourselves responsible activists," Visco said. ([NIH Record, 1998](#)) The NBCC lobbied vigorously and successfully for expanded federal breast cancer research funding.

Breast cancer incidence was perceived to be high in many communities on Long Island at that time. 1 in 9: the Long Island Breast Cancer Action Coalition, named for what was then the estimated risk of a woman's developing breast cancer, was founded in 1990. In 1992 Lorraine Pace organized a group of volunteers to map almost 9,000 households in West Islip, Long Island. Using color-coded markers to indicate breast cancer status, they amassed a statistically significant response of 5,082 questionnaires, conferring scientific credibility upon their activism. ([New York Times, 2006](#))

In response to lobbying by these and other activists Congress mandated the Long Island Breast Cancer Study Project (LIBCSP) in 1993. The Long Island advocates were given an unprecedented level of responsibility for aspects of the research design. LIBCSP consisted of 10 initiatives, including epidemiologic studies, and was among the first federally-funded environmental research into breast cancer ([Brody EHP 2005](#))

In 1993 members of the Massachusetts Breast Cancer Coalition created a laboratory of its own. Alarmed by reports of elevated breast cancer rates in 11 of 15 towns on Cape Cod, the Coalition created the Silent Spring Institute to study the links between the environment and women's health, beginning with breast cancer. The Institute quickly developed a team to lead the Cape Cod Breast Cancer and Environment Study and the Newton Breast Cancer Study with funding from the Massachusetts Department of Public Health. Silent Spring's process required scientists to work closely with the community – an unfamiliar paradigm for both groups. ([Silent Spring Institute](#))

Using geographic information system (GIS) technology, Silent Spring researchers integrated breast cancer and environmental data to estimate what appropriate incidence rates would be. They documented breast cancer incidence rates on Cape Cod that were consistently higher and used those findings to set priorities for further environmental and epidemiologic research. ([Brody, 2005](#))

Francine Levien founded Zero Breast Cancer in 1995, together with a small cadre of women with breast cancer who were concerned about the high incidence in Marin County. Zero Breast Cancer was founded with and maintained a nearly-exclusive focus on identifying environmental factors and the role they could play in the initiation and progression of breast cancer.

The California Breast Cancer Research Program (CBCRP), founded in 1993, allied itself with the breast cancer advocacy community. CBCRP provided funding for the 1997 pilot of the survey-based Adolescent Risk Factors Study, one of Zero Breast Cancer's first major undertakings. The study employed a survey to measure environmental factors including the lifestyle factors. Subjects answered questions about their exposures to risks during adolescence and adulthood, growth histories, physical and social environment and personal habits, including smoking and drinking. As the study's funder, CBCRP required researchers to use the Community Based Participatory Research (CBPR) process, which spurred new levels of communication between scientists and activists. (*personal conversation with Janice Barlow, 2008*)

All these new relationships, collaborative research projects and methodologies for involving community members built momentum for the NIEHS director's vision of science that would be responsive to the American people.

## Political will: the leadership of Dr Ken Olden

Dr Olden was named director of the NIEHS in 1991. As a cell biologist and biochemist he was active in cancer research for almost thirty years. He consistently demonstrated his respect for public concerns about the potential role of environmental chemicals in breast cancer development.

Dr. Olden conceived of many bold and innovative mechanisms to make his institute's science responsive to the American people...The NIEHS has established itself as a leader in promoting the importance of collaborations between researchers and communities. ([Cranmer, EHP 2005](#))

The specific idea for the Centers arose from a one-day brainstorming session held in April 2002 co-chaired by Dr. Olden and the NBCC in Charlotte, North Carolina. Patients, patient advocates, breast cancer specialists and scientists met and explored the notion of Centers of Excellence for the study of breast cancer. Attendees suggested looking "upstream" in the life of a person who develops cancer. Something, they said, sets her apart: given the same environment exposures, other women will be free of cancer. The question became not just *how* but also *when* does cancer begin?

In North Carolina Dr Olden expressed his hope that any future NIEHS-led breast cancer research initiative would include participation from the public as well as many groups in the scientific community. ([NIEHS report](#)) Some attendees expressed concern about the difficulty in obtaining funding for the type of long-term interdisciplinary research needed. ([Hiatt, EHP 2005](#)) NIEHS staff noted these concerns and recommendations as they continued to plan a new research program.

In May of that year NIEHS, the Center on Environmental Health Sciences at University of California Berkeley (COEH), Centers for Disease Control and Prevention and the International Agency for Research on Cancer sponsored the meeting "International Summit on Breast Cancer and the Environment: Research Needs." The Summit brought together experts from a wide array of disciplines, once again with substantial input from the advocacy community.

Advocates at the Summit asserted that researchers have *an obligation* to share results with the community. (*personal conversation with Janice Barlow, 2008*) By using CBPR, they said, research results would a) be made understandable to the public; b) become part of a feedback loop. As part of the Summit the NIEHS reported on its plans for breast cancer research centers that would incorporate community participation and employ a transdisciplinary approach.

The tone of the national discussion changed somewhat when, in August, results of the LIBCSP were published. The data provided few of the definitive answers that activists had hoped for.

The most comprehensive study ever conducted to look for a direct connection between breast cancer and several environmental toxins has ended up with largely negative results. And while that has breast cancer activists frustrated, it has also provided researchers with a wealth of data to mine in hopes of finally pursuing new directions... ([Twombly, JNCI 2002](#))

As a result of the LIBCSP findings researchers refined their hypotheses about the interplay between environmental toxins and other factors in the development of breast cancer. Mention of the findings was added to the formal report of the Summit.

While the Long Island study does not fully explain which toxic chemicals are contributing to the breast cancer epidemic, it is a first step in beginning to discover the scientific evidence we need to stop the breast cancer epidemic. The next step is to ensure that future research on environmental links to breast cancer be informed by the principles of

CBPR with representatives of the affected community as partners throughout the process.

Zero Breast Cancer Director Janice Barlow extended the invitation that brought Dr. Olden and the Town Hall Meeting to Marin County in 2002. He met there with the 200 or so predominantly well-educated and well-informed community members and breast cancer advocates.

No additional funds were designated by Congress during this period but Dr. Olden managed to redirect NIEHS project funds toward a breast cancer research program. He shared that program's design with colleagues at the National Cancer Institute and their enthusiasm resulted in additional funding.

With those accomplishments in mind Dr Olden announced the imminent release of a Request for Applications (RFA) for Breast Cancer and the Environment Research Centers to an excited and grateful group in Marin County.

### **Success by design**

The Centers were unusual from their conception. Dr Olden and the NIEHS knew that success required excellent communication among stakeholders. They placed a high value on organizational styles that allowed the community perspective to influence the development of research. They envisioned a project in which basic science would inform epidemiology and vice versa, and in which scientific findings were effectively conveyed, or "translated" to the community.

To help ensure that level of communication the RFA mandated a Community Outreach and Translation Core (COTC) at each center. For Dr Olden as well as advocates, a successful COTC was essential to a successful project.

(BCER Centers) have extended the democratization of science in ways that can offer models for the development of new norms for environmental health research: public empowerment that goes beyond mere involvement on advisory boards, a shift away from purely investigator-defined research to joint activist-scientist definition of research problems, and integration across disciplines and across institutions. ([Brody, EHP 2005](#))

The guidelines for applicants also specified inclusion of basic science and encouraged transdisciplinary epidemiology. The NIEHS evaluated bids from 13 sites and, as anticipated, awarded four: to the University of Cincinnati, Fox Chase Cancer Center, the University of California, San Francisco and Michigan State University.

### **A united effort**

It was another hot, sunny October day in Marin County when the news was announced. The press conference drew a crowd: breast cancer advocates, community members, environmental justice and healthcare workers all wanted to hear the exciting news firsthand. A dozen reporters from local television and radio stations and newspapers jockeyed for position and competed for interviews with the experts. Today they would be able to report good news: expanded research toward a solution to the Bay Area's mysteriously high incidence of breast cancer.

As he addressed the press and the public the morning of Tuesday, October 14, 2003 Dr Olden acknowledged the breadth of expertise represented at the Centers. All four centers would work in close cooperation, he said, making a united effort to understand environmental underpinnings to breast cancer vulnerability.

Representative Lynn Woolsey joined him on the podium. "Marin County is the perfect Petri dish for this study," she told a reporter.

Meeting one another face to face for the first time that day were the new BCERC Principle Investigators: Sue C. Heffelfinger, M.D., Ph.D., University of Cincinnati; Jose Russo, M.D. Fox Chase Cancer Center, Philadelphia; Robert A. Hiatt, M.D., Ph.D., University of California, San Francisco and Sandra Z. Haslam, Ph.D., Michigan State University.

Many of the future Bay Area BCERC partners came as well, including staff from Kaiser Permanente of Northern California, Marin County Department of Health and Human Services, the Bayview Hunters Point Health and Environmental Assessment Task Force, Breast Cancer Fund and California Department of Health Services. Zero Breast Cancer hosted a reception after the announcement.

FOR IMMEDIATE RELEASE, Tuesday, October 14, 2003

*NIH-Funded Centers to Seek Early Environmental Exposures That May Lead to Breast Cancer*

National Institutes of Health Director Elias A. Zerhouni, M.D., today announced the funding of four new Breast Cancer and the Environment Research Centers to study the prenatal-to-adult environmental exposures that may predispose a woman to breast cancer. (*NIH news release*)

*The BCERC today is researchers at four universities, clinical partners in four additional states and hundreds of breast cancer and environmental justice advocates, all committed to determining the role of environmental factors in the onset of puberty in girls as a window to better understanding the development of breast cancer and ways to prevent it. It includes the men and women of the NCI and NIEHS and those from the Avon Foundation, who have created a public-private partnership by making donor-directed donations to NIEHS for BCERC, funding community advocate involvement and coordination of studies into the role of possible environmental and genetic factors and future risk of breast cancer. The seven-year grants are due to expire in 2010.*