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U.S. to Finance Project to Study Breast Cancer On Long Island

By PETER MARKS,

On the day she learned she had breast cancer, Lorraine Pace began to gather evidence.

She drove home from her oncologist's office, filled a bottle with tap water from her kitchen sink and, hoping it might someday provide a clue as to how she contracted the disease, stored it in a cabinet above the stove.

A year and a half later, the bottle is still in the cabinet. And though Mrs. Pace still does not know what caused her cancer, her own research over the last 18 months has made her even more suspicious that something in the environment -- perhaps even the rust-colored silt at the bottom of her water sample -- played a role in her illness.

Mrs. Pace may soon find out if she is onto something. Large-Scale Study

In a reversal of its previous policy, brought about largely by an increasingly vocal network of breast-cancer survivors like Mrs. Pace, the Federal Government is embarking on a large-scale examination of a question that vexes hundreds of women who have contracted the disease on Long Island: Is the high incidence of breast cancer here traceable to some problem in the soil, water or air?

The dedication of so much money to the Federal effort -- officials of the National Cancer Institute estimate that at their peak, the studies could run several million dollars a year -- comes less than a year after the Federal Centers for Disease Control and Prevention concluded that there was no need for an extensive study of breast cancer here.

Acting on the recommendations of a panel of epidemiologists, the Federal agency had determined the high incidence of the disease in Nassau County, where the breast cancer rate is 20 percent higher than the state rate, could be attributed largely to known risk factors like heredity. Suffolk County's rate is lower than Nassau's, but still higher than the state's.

But those findings outraged women's organizations and breast-cancer survivors on Long Island who have become highly organized around the issue of committing more resources for prevention, and not just detection, of a disease diagnosed in 146,000 women in the United States each year. The women's groups criticized the findings as reflective of what they viewed as the dismissive way the medical establishment has treated concerns about the origins of the disease.

"We know how to increase our chances of getting lung cancer," said Mrs. Pace, 52, areal-estate saleswoman and head of the West Islip Breast Cancer Coalition, which has documented hundreds of breast cancer cases among women in this community of 28,000 on Long Island's South Shore. "But we don't know what we did to increase our chances of getting breast cancer. And we feel, as women, we have the right to know." Groups Cite Obstacles

Some advocates said that those seeking funds for breast cancer research faced the same obstacles as those who lobbied for money for AIDS research. "The more we learned, the more astonished we were at how little had been done on preventative research for breast cancer," said Jeanne Doremus, who heads the Noreen T. Holland Breast Cancer Foundation, a philanthropic group founded on Long Island by friends of the organization's namesake, who died of breast cancer.

The foundation awarded its first grants, totaling \$35,000, in September; two of the three projects involved research into possible environmental links to breast cancer.

Under pressure from Senators Tom Harkin of Iowa, Alfonse M. D'Amato of New York, and others who took up the women's cause, Federal officials earlier this year decided to pursue a comprehensive study on Long Island, a project that some scientists and others regard as among the most ambitious of its kind. In the coming months and years, researchers will engage in a variety of studies on Long Island, testing radiation released by everyday appliances; sampling pesticide levels in the dust in household carpeting, and looking for chemical contamination in the drinking water in Long Island homes.

The National Cancer Institute recently awarded its first grant, for \$1.26 million, to Dr. Lee Caplan, an epidemiologist at the University Medical Center at Stony Brook, who will lead a four-year study that will examine whether pesticides or electromagnetic fields from appliances or overhead transmission wires play a role in breast cancer. In addition, the cancer institute, jointly with the National Institute of Environmental Health Sciences, is soliciting proposals for an even broader environmental investigation, to be called the Long Island Breast Cancer Study Project. The cost of the project has yet to be determined. Chasing Risk Factors

"It's more challenging, more comprehensive than most of the research we undertake," said Dr. Iris Ostrom, the cancer institute's chief of extramural programs and director of the Long Island project. "And we will have to draw on a multiplicity of types of expertise to carry this out."

No one knows how long it may take to pinpoint an environmental cause for breast cancer, but some breast cancer experts believe such a link is very likely to be discovered. At a conference last week at Adelphi University on breast cancer and the environment -- the first in the nation, organizers said, to bring together scientists and grass-roots women's groups to discuss avenues of research -- scientists reported that about 30 percent of breast cancer cases could be traced to known risk factors, like ethnic background, heredity and diet.

"What we're really asking is, what are the risk factors of the other 70 percent?" said Devra Lee Davis, a senior health adviser in the Clinton Administration and a co-chairwoman of the conference.

During the two-day symposium, which drew researchers from government and universities, the breast cancer experts offered a lengthy list of potential contributing factors, from toxic industrial waste to chemicals in household cleaning products, that must undergo rigorous study. **Canvassing for Facts**

"Breast cancer is a puzzle of enormous complexity," Dr. Susan Love, director of the Breast Center at the University of California at Los Angeles and the other co-chairwoman, told reporters at a news conference last week. "We don't really have a clue as to what the factors are. What we're trying to do is broaden the question to ask, what is wrong with society that causes this?"

To women like Mrs. Pace, the answer is of vital concern. In the last year, she and a dozen other women, many of whom have had breast cancer, have been canvassing and re-canvassing the neighborhoods of West Islip, asking questions about the disease and trying to do what few other researchers have ever done: Provide a statistical portrait, in map form, of the impact of breast cancer on a single community.

When the survey is completed in the next month or so, she and other coalition members plan to submit the map to the researchers at Stony Brook, who have expressed interest in seeing what the coalition finds.

Mrs. Pace hopes the data will help unlock some of the secrets, and maybe, even help in determining whether there is an environmental link. "It's very frustrating to have a disease and not know where you got it," she said. "The anger is so intense you can't believe it."