the Northwest Indian Fisheries Commission and co-chairs the CTC, was especially upset that Alaska unveiled its new system in March and implemented it in July. "Alaska more or less dropped this on everyone," leaving no time to evaluate it, he says.

While Canadian and tribal scientists argue that science is at the heart of the salmon controversy, Alaska says politics is really driving the court case. "There is a thin line between science and politics," says Scott Marshall, southeast regional supervisor for commercial fisheries management in the Alaska Department of Fish and Game, and "a few of the Canadian and Washington scientists just stepped over that line." In his closing remarks, Alaska attorney Michael Stanley told the judge that "shutting down Alaska fisheries will do nothing to rebuild stocks down south." He used charts and graphs to show that even if Alaska cut its quota by 50%, the depleted Washington and Oregon runs would increase by only a few hundred fish. The real cause of those dept ted runs, Stanley argued, is the damming of major salmon rivers in the Pacific Northwest for hydroelectric power.

While recognizing that the dams have contributed to the decline, the tribes say the entire region—including Alaska—needs to make an effort toward conservation. "Alaska is fishing above the model, and it has an accumulative effect. We all have to work together toward rebuilding," says Katherine Brigham, the tribal alternate for the Pacific Salmon Commission.

Apparently, Judge Rothstein agrees. In a 36-page decision issued on 7 September, Rothstein ruled that Alaska's fishery should remain closed for the rest of the season. Alaska, Rothstein wrote, failed to make "a good-faith effort" to help rebuild the salmon stocks in the entire region. "The court finds it reasonable that Alaska wanted to explore alternative models or refinement of the CTC model. However ... Alaska acted unreasonably in the manner in which it attempted to implement its 1995 plan," Rothstein wrote. She said the dispute should be resolved through the Pacific Salmon Treaty process.

Alaska attorneys say they plan to appeal the decision. But whatever the outcome of the battle over the 1995 Alaska catch, the underlying dispute could threaten the future of salmon fishing in the entire region. The United States and Canada have agreed to appoint a mediator to help settle their dispute. But on the U.S. side, a precursor to the treaty requires Washington, Oregon, and Alaska to shut down their salmon fisheries if they can't agree on the allocation of catches by 1998. In that case, the issue is sure to remain firmly in the hands of the lawyers.

–Lisa Busch

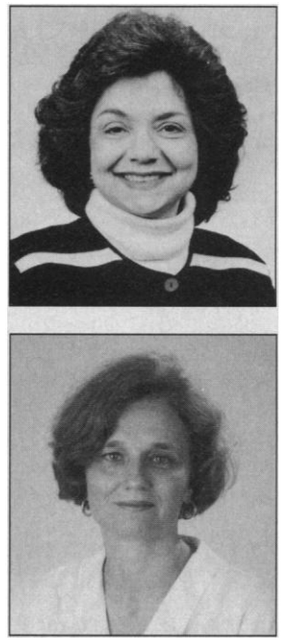
Lisa Busch is a science writer based in Alaska.

BIOMEDICAL RESEARCH

Breast Cancer Activists Seek Voice in Research Decisions

MINNEAPOLIS—The president of the National Breast Cancer Coalition addressed her audience as a field commander might welcome new troops. "I think about you as sort of the Delta Strike Force, the Green Berets, the elites," Fran Visco told a group of women gathered in a hotel meeting room here in mid-July. But the battle plan Visco presented is not so much an all-out attack on an enemy camp as a campaign to infiltrate the ranks of an ally: the cancer-research establishment.

"What we're trying to form," Visco told the women, "is a group of breast cancer advocates across the country who are educated and informed, who can work side by side with scientists in charting the course of breast cancer research." As Visco and her colleagues see it, the rising incidence of breast cancer in the United States—the lifetime risk has climbed from one in 20 at the end of World War II to one in eight today—is evidence that a new strategy is needed to win the war on breast cancer.



LEADers. Fran Visco (*top*) and Kay Dickersin developed program to train advocates.

Visco, a Philadelphia attorney and breast cancer survivor, and the coalition she heads have already had a major impact through an effective lobbying campaign that has increased federal funds for breast cancer programs. Now their goal is to play a role in deciding how those funds are spent. And that's where Visco's "Delta Strike Force" comes in. The 38 women in her audience were among the first to take part in Project LEAD (Leadership Education and Advocacy Development), which begins with a 3 1/2-day workshop designed to give breast cancer advocates enough knowledge of science and the research process to enable them to participate at every level. Visco expects Project LEAD trainees to join local boards that review research on human subjects, planning committees, and peer-review study sections of the National Institutes of Health (NIH). But some scientists do not consider it wise to invite such novices into the inner sanctum.

Even researchers who welcome advocates on advisory committees are wary of having them involved directly in scientific decision-making. They argue that the gold standard by which any scientific effort is judged is peer review, not peer-and-other-interested-parties review. But the coalition's leaders dismiss such concerns. "Yes, it is" a radical approach, "but it shouldn't be," says Kay Dickersin, a University of Maryland epidemiologist who designed Project LEAD. Dickersin is a breast cancer survivor and founding member of the coalition, which has 270 member organizations representing thousands of women around the country. Scientists think "we can help set programmatic goals but [that] we don't know enough about science to judge it ... and we're here because we disagree with that," Dickersin told the women attending the workshop.

Deeper involvement. Project LEAD is a new twist on an established trend of public involvement in biomedical research. Activists have long shaped the landscape by raising funds to combat specific diseases, lobbying Congress to earmark funds, even creating new NIH institutes focused on "their" disease. But, with AIDS groups leading the way, activists in the late 1980s began to get more deeply involved in the planning of research, gaining representation on scientific advisory committees.

The Breast Cancer Coalition has been one of the more successful and aggressive of this new breed. Federal spending on breast cancer research was about $90 million a year when the coalition formed in 1991. Now it's about $475 million, largely due to the lobbying efforts of Visco and her colleagues. The coalition's most spectacular success was to persuade Congress in 1992 to add $200 million to the Department of Defense's (DOD's) budget to fund a new breast cancer research program (*Science*, 29 January 1993, p. 616).

Reaching for the reins in 1993, the coalition lobbied for the creation of a multiagency National Action Plan on Breast Cancer. They gained support from the White House and the Capitol, where 52 senators and more than 200 members of Congress signed letters of support. Health and Human Services (HHS) Secretary Donna Shalala

convened a meeting to develop the plan, which aims to get consumers, scientists, government officials, and industry leaders working on a common program.

Visco and Susan Blumenthal, a deputy assistant secretary at HHS, are the plan's co-directors. Last month, Visco helped decide which of more than 600 proposals on topics ranging from breast cancer etiology to patient advocacy would be funded with the $10 million that the National Cancer Institute (NCI) made available this year on orders from the Administration. And, in a nod to the movement's growing clout, the Administration has named Visco and Dickersin to the nation's top cancer research advisory committees: Visco to the President's Cancer Panel, in 1993, and Dickersin to the NCI's National Cancer Advisory Board, in January.

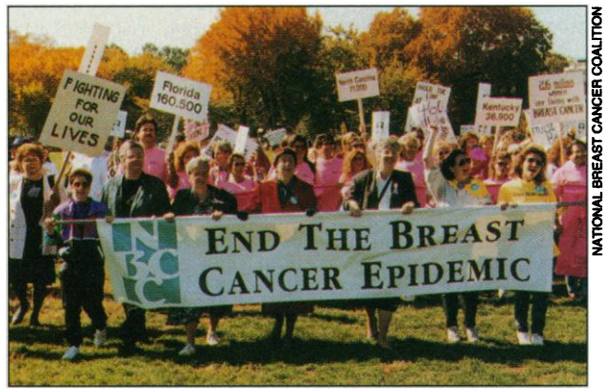
Advocates are also gaining a foothold on committees at the more detailed planning levels. The DOD breast cancer research program, for example, involves consumers on panels that review proposals for relevance to the program's objectives, and advocates expect to be included in its peer-review study sections when they meet in November. The national Breast Cancer Prevention Trial, a massive clinical trial to test whether the drug tamoxifen can prevent breast cancer in healthy women, has a participants' advisory board that has provided "an aspect to the trial that none of us who aren't participants could bring to it," said NCI's Leslie Ford, who oversees the trial. And the Food and Drug Administration is exploring new ways to include breast cancer and other advocates on its Oncology Drugs Advisory Committee—possibly as voting members of subcommittees deciding on new treatments.

LEADership training. The National Breast Cancer Coalition established Project LEAD to coach breast cancer activists to be more forceful members of such partnerships—and to ensure that scientists take them seriously. As Visco told the troops in July: "They [scientists] think we're going to be there to scream. They think we're going to be there to bare our breasts. But what we want is to make sure the money we fought so hard for isn't wasted. ... What we want is answers."

But Project LEAD aims for more than the traditional goal of ensuring that patients' perspectives are well represented in clinical trials. Dickersin says the coalition wants to install advocates on all committees that review and approve proposals for breast cancer research. Their presence, she says, would remind researchers why they are conducting research in the first place. And she thinks the scientific community would benefit by involving the public in its concerns.

Women are chosen for Project LEAD based on what they have achieved in their own communities. For example, Doris Rosenbaum, a breast cancer survivor who trained here in July, has lobbied successfully in Kentucky for insurance coverage for mammograms and for state-funded screenings for poor and rural women. While Rosenbaum isn't sure where Project LEAD will take her, she is committed to its broad goals.

By the end of this year, about 150 women like Rosenbaum will have taken part in the project. The first workshop was in Los Angeles in June; the next two will be in Washington, D.C., next month, and in Nashville, Tennessee, in November. Four more are planned for next year. The workshops consist of lectures and discussion groups, with topics ranging from cell division and death to why clinical trials are randomized and how to figure the cost-effectiveness of a mammography screening program in a given community.



NATIONAL BREAST CANCER COALITION

Growing clout. Through grass-roots activism, the National Breast Cancer Coalition has increased research funding.

The aim of Project LEAD is not to turn advocates into scientists, Dickersin said, but to give women the knowledge base to take part in scientific discussion. "We think we can make research better by being part of the research process," she said. "We think we can really improve what's being done."

Will researchers follow? Members of the cancer-research establishment say they agree with Dickersin's assessment—to a point. Richard Klausner, the newly appointed NCI director, said in an interview that he wants advocates involved with his agency "in a very real way." His initial meetings with Visco and other coalition members "have been tremendously productive ... and I foresee us working together closely and well," he added. But a blanket policy prescribing advocates' involvement in peer-review and all other decision processes? Klausner doubts that would work. "I don't think it necessarily makes sense" to assign an advocate for every disease to every study section that may match his or her area of interest, Klausner said. "Science doesn't neatly divide up that way."

Some NIH leaders have gone out of their way to maintain good relations with patient advocates, including Francis Collins, director of NIH's National Center for Human Genome Research and a scheduled lecturer at next month's workshop. Collins works alongside advocates on various panels of the genome project and on the National Action Plan's hereditary susceptibility committee, where a breast cancer survivor recently "helped us [scientists] understand what it's like to have your own DNA used without your knowledge and approval." Collins credits the coalition with recognizing "that the credibility of the advocates is crucial ... [that advocates must be] both passionate about the issue and also extremely well informed."

But Collins, like Klausner, does not favor involving advocates at every level of research decision-making. He suggests there's a limit to what non-specialists can contribute. For example, he said he himself would be uncomfortable taking part in a study section on structural biology, "which depends on a fairly abstract group of concepts, which I personally would be unable to review."

Nor is there universal support for Project LEAD's objectives out in the trenches where the war on cancer is being fought. National Cancer Advisory Board member Sydney Salmon, director of the Arizona Cancer Center in Tucson, is one of many skeptics. Although activists have helped generate funds for breast cancer studies, Salmon isn't sure such earmarked projects—or the political strings that come attached—achieve the desired results. For example, Salmon noted that the discovery of an important factor in breast cancer—the loss of tumor-suppressor genes—was made by scientists studying a rare and seemingly unrelated childhood eye cancer called retinoblastoma. His point: Good intentions do not always yield good science. "The most interesting and innovative ideas that have revolutionized biomedical research have by and large come from scientists," Salmon said, "and not from bureaucrats—be they from government or advocate groups."

Mindful that the scientific community is wary, Visco and the coalition are nevertheless determined to become part of its creative process. They know it won't be easy. At Project LEAD's Sunday morning graduation ceremony, Visco gave advocates a final word of advice to consider when they sit down with scientists. "As consumers, you walk into the room with a disadvantage," Visco told the women. "You have to earn the credibility and respect that those few letters after their name give them."

–Jane Erikson

Jane Erikson is a medical writer with the Arizona Star *in Tucson.*