

# The Politics of Breast Cancer

A grass-roots movement consisting mostly of breast cancer survivors persuaded Congress to double funds for the disease; its success is rattling the biomedical research establishment

When Kay Dickersin went to a gathering in Washington in May 1991, she wasn't quite sure what she was getting into. The meeting had been billed as a group of women who wanted to influence government policy on breast cancer research. And that was a subject in which Dickersin had a keen—and keenly personal—interest. Four years earlier she had had surgery after a diagnosis of breast cancer. It struck out of the blue: Dickersin had no family history of breast cancer, nor any of the usual warning signs or symptoms. One thing she did have, though, was knowledge: She was a Ph.D. student in epidemiology at Johns Hopkins when she was diagnosed, and she had “reams of files” on breast cancer, which she had collected out of an interest in the subject. It was the combination of personal experience and expertise that she wanted to put at the service of the informal gathering of women in Washington.

That combination of personal drive and technical knowledge has become a hallmark of the informal group Dickersin joined, which, 1 year later, has become the most visible lobby to stalk the National Institutes of Health (NIH) since the AIDS activist group ACT UP began making a loud noise in the streets of New York. The National Breast Cancer Coalition (NBCC), as it's known, along with other groups, achieved a breath-taking political victory: They lobbied Congress and persuaded it to double the amount of money it spends on breast cancer research. Some of the increase went to the National Cancer Institute (NCI), raising its breast cancer budget from \$133 million to \$197 million, but by far the larger amount (\$210 million) went to the Department of Defense, to be administered by the U.S. Army (*Science*, 30 October 1992, p. 732).

But along with that success has come conflict: between activists, who are demanding a role in deciding how research money should be spent, and scientists, who stoutly defend the existing system. At a recent meeting, for example, Frederick Becker, research chief of the M.D. Anderson Cancer Research Center in Houston, said: “The tidal wave of advocacy...may wash away certain bulwarks of basic science that have been the greatest contributors towards the potential for cancer prevention and cure....” Their chief worry is that popularity rather than quality could become important in determining what gets funded, and that these targeted funds could

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siphon dollars from other basic research.

And there are conflicts even within the psyches of those who, like Kay Dickersin, are both scientists and breast cancer activists. As a scientist, Dickersin says she finds it “painful” to be identified with a political movement that aims to target research into one area. But she says that experience has shown her that the cancer research program needs shaking up. She agrees with well-known surgeon Susan Love, a fellow NBCC member, who says the coalition wants to break open what it regards as NCI's cliquish inner circle and bring in new faces. “We have to stop business as usual. We have to change the direction and really put our emphasis on basic science and prevention, and not such a large emphasis on treatment,” says Love.

Dickersin is also motivated by the fact that two of her sisters have since been diagnosed with breast cancer and the fourth and youngest sister waits, fearing the worst. It's incredibly frustrating, Dickersin says, to think that “we have to sit and wait for each sister to get it, and others have to sit and wait for their daughters to get it,” while nothing seems to change. She knows women in NBCC with breast cancer—daughters of women who died of it—who are “getting the same chemo, the same radiation” their mothers got. They fear

their daughters will get caught in the same mill. That feeling makes them angry, and it drives their political movement.

## Political prowess

Anger, of course, isn't enough on its own to drive a political movement. In NBCC's case, its clout stems from several other factors as well. One is numbers. Breast cancer is one of the commonest cancers, striking 180,000 U.S. women each year, killing 46,000, and leaving in its wake a survivor group of 1.5 million. NBCC established a broad base with captains in every state. A second factor is political know-how, which comes from people like Fran Visco, a litigator for a Philadelphia law firm who is now NBCC's president. Third is a strong dose of scientific and medical expertise, contributed by volunteers like Dickersin and Love, who cochair NBCC's research committee.

But even this constellation of factors might not have been enough if NBCC hadn't hit Washington at a time when its targets were vulnerable to a push in the right direction. NIH had declared that women's health needed more attention. And, in 1992, many senators were trying to overcome the embarrassment of the Clarence Thomas-Anita Hill hearings, proving to constituents that they cared about women's issues. The chairman of the Senate appropriations committee in charge of NIH funding—Senator Tom Harkin (D-IA)—had seen two sisters die of breast cancer and was determined to help the cause.

In exploiting this opening, NBCC president Visco and Joann Howes, a political consultant at the Washington firm of Bass and Howes, say they consciously followed the tactics of AIDS activists. To get their foot in the door, they had to show they had broad support, which they did in the fall of 1991. They solicited written appeals for increased NCI spending on breast cancer, hoping to get 175,000 letters; instead, in 6 weeks they received 600,000. They delivered them to the White House and Congress, then followed up with a technical meeting to establish scientific credibility.

In one of NBCC's key decisions, the group organized its own “research hearings” on Capitol Hill in February 1992. The activists invited top researchers to come and speak, asking whether the field could use more funds. Fifteen spoke, including Marc Lippman of Georgetown University, Maureen Henderson of the Fred Hutchinson Cancer Research

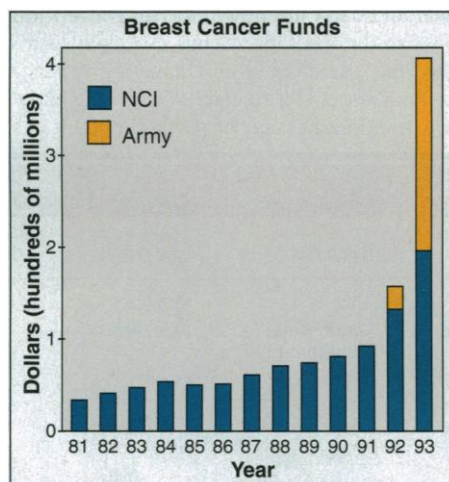
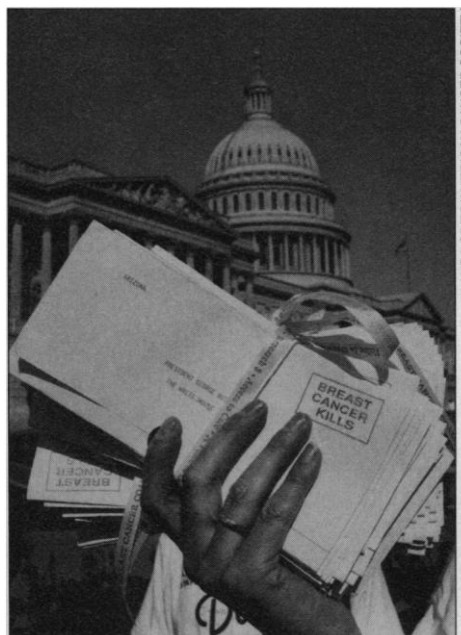
Center in Seattle, Darcy Spicer of the University of Southern California, and Graham Colditz of Harvard. To no one's surprise, they revealed that their work could use additional funding. NBCC came up with a proposed 1993 increase for NCI of \$300 million, spelling out categories into which it should be put.

The number may have sounded like pie-in-the-sky to many old timers. But, thanks to Senator Harkin's skillful maneuvering, Congress came through with more than two-thirds of the sum the coalition was asking for. Because Congress had agreed to a cap on domestic spending, however, the money ended up in the defense budget. Pentagon defenders like Senator Daniel Inouye (D-HI) objected that it was wasteful and brazenly political to carve up the military budget this way, even for a good cause like medical research. But Harkin pointed to a clause already approved by military stalwarts in the House that earmarked \$25 million in Army money for breast cancer research in 1993 and set aside another \$7 million for an unnamed "institution in the Northeast." Though no document says so, any appropriations committee aide can tell you the phrase refers to the University of Pittsburgh, whose interests are guarded by two members of the defense appropriations subcommittee: chairman John Murtha (D-PA) and ranking Republican Joseph McDade (R-PA). It became clear that opposition to Harkin's move was not so much a matter of principle as who would get the funds—and how much. Once this became clear, the Senate debate came to an end and Harkin's proposal won.

As a result, the Army now has a new mission and \$210 million to spend on it. Because it doesn't have a peer-review system comparable to NIH's, the U.S. Army Medical Research and Development Command (USAMRDC) is asking for some help from the Institute of Medicine (IOM). General Richard Travis, USAMRDC's chief, told *Science* in a recent telephone interview that in December IOM agreed to pull together an expert panel that will first, rule on the appropriateness of his strategy for spending the money, and second, advise the Army on how to organize and conduct a peer-review program. Travis says his strategy is to avoid duplicating basic scientific research of the kind done at NCI and to focus instead on "mid-risk, high-pay-off" projects. However, if the IOM advisers tell him he should focus exclusively on basic science, he's ready to do that instead. Travis hopes to begin soliciting proposals next spring. The one kind of project he does not intend to fund is the "bricks and mortar" variety.

#### A seat at the table

Having won money for their cause, the activists are not about to stop there: They want a say in how the funds are spent. At a meeting of NCI's National Cancer Advisory Board (NCAB) on 14 December, NBCC leaders



**Cause and effect.** Activists lobbied for a big increase; \$210 million ended up in the Army.

Visco and Love laid out a manifesto of proposed changes. Members of the board were shocked to learn how intimately the activists want to become involved.

NBCC wants at least two study sections (volunteer science panels that conduct NIH's peer review) devoted to breast cancer, and they want their own members invited to sit on these panels. This would set a new precedent for NIH, and Samuel Broder, NCI's director, grumbles that people who want to do this just "don't understand how NIH works." By definition, peer review must be conducted by people with expertise in the area under review, Broder says, though he welcomes nonexperts on oversight panels like the NCAB. Here, again, he faces new demands: Cancer activists want a seat on the NCAB, and they also want an NCAB subcommittee devoted exclusively to breast cancer. They would like to be included in groups that monitor data coming in from ongoing clinical trials. They hope to

establish a "formal mechanism" through which to exchange information and advice with Broder. And they want every significant subsegment of NCI to have "consumer input."

Some of these requests have upset biomedical leaders such as Becker of the M.D. Anderson Clinic and a member of the NCAB. He says others scientists have told him they agree with an impassioned speech he gave at the advisory board meeting last month, in which he stressed the importance of nontargeted research. He pointed out that some discoveries crucial to understanding breast cancer today—such as information about oncogenes and tumor suppressor genes—came out of highly specialized work on adenoviruses and retinoblastoma. He worries that the trend toward earmarking funds will make it harder to support speculative research.

NCI chief Broder, though he is trying to calm these troubled waters, also is concerned that the emphasis on breast cancer may lead to neglect of basic biomedical science. He notes that "our commitment to breast cancer has increased 177% in recent years" while NCI's overall budget has grown 35%. He worries about the lack of "balance" that's creeping into the budget, citing the cutback this year in NIH's general medical science funds as an indicator of potential trouble in the future. Trying to respond to changing political winds, he worries, could erode the agency's research strategy and deprive esoteric fields of support. Yet Broder agrees that "we have to have an open dialogue" with the patient activists, pointing out that it was he, after all, who invited them to address the NCAB.

Broder has clearly heard the message. Last September, he submitted an NCI budget request for 1994 that seems to go a long way toward doing what the breast cancer lobby would like. The total amount requested for breast cancer research, for example, jumps from the \$197 million appropriated this year to \$449 million. In addition, NCI is coordinating a new, NIH-wide program to attack breast cancer. It is also launching a series of "specialized programs of research excellence" (SPORES) aimed at getting the latest science into clinical trials and treatment practices as rapidly as possible, the first batch of which will be focused on breast and prostate cancer.

Although Broder says these changes are coming about because "a number of opportunities in breast cancer are unfolding," it's clear that some of them may not be purely scientific opportunities. After meeting with NCI's top brass and reviewing the budget recently, Susan Love says, "They are listening; the dialogue is starting." Broder has proposed an aggressive new plan, which, according to Love, is "exactly the kind of thing we want to see." Now the coalition is gearing up for another lobbying effort in 1993 to make sure that NCI's aggressive plan gets funded.

—Eliot Marshall