

The loud voices: From movie stars to Washington's best-known women to breast cancer advocates, these outspoken survivors have put breast cancer on the national agenda



# the breast GENE

Will women's sheer determination be the key that finally unlocks

By Kathleen McAuliffe

**W**hen NBC correspondent Betty Rollin got breast cancer in 1975 at age thirty-nine, she knew of no one else with the disease except for political wives Betty Ford and Happy Rockefeller. "Today," says Rollin, who chronicled her experience in the best-seller *First, You Cry*, "I almost don't know anyone who hasn't had breast cancer."

It's an epidemic, we're told. It's the chic new charity, eclipsing even AIDS for research dollars. It's everywhere in the media: the rallies; the parade of celebrities disclosing their private battles against the disease; the giant billboards of Linda Evangelista, with only an arm draped across her gaunt model's

chest, accompanied by a toll-free number to call with donations toward a cure. In case the message hasn't reached everyone, breast cancer even has a month—October—devoted to boosting public awareness.

What's going on here? How did a hazard that barely registered as a blip on the nation's radar screen just a generation ago mushroom into such an ominous cloud?

In 1970, when it was rarely discussed, breast cancer was hardly rare. Then, one in thirteen women fell victim to the disease by age eighty-five. The numbers are one in eight today. But even that increase alone does not account for the attention now being paid to the disease.

Photo credits, page 126.



# cancer RATTON

**the breast cancer cure? It has certainly brought us progress**

In reality, the furor and clamor over breast cancer is tapping something much deeper in the female psyche. Striking at the very core of women's feminine identity, breast cancer makes us feel uniquely vulnerable—so much so that “nice ladies” once just didn't talk about it. “Twenty years ago,” says Amy Langer, director of the National Alliance of Breast Cancer Organizations (NABCO), in New York City, “cancer itself was a taboo subject, and breast cancer was particularly taboo because it affects a part of the body we associate with intimacy, sexuality and nurturing.”

The disease also relates to issues of feminine anger, because the fight against it has become inextricably intertwined with

women's own battle for sexual liberation and empowerment within society. It can even make some women feel guilty and further victimized, for the very lifestyle choices that they associated with their emancipation—the postponement of child-bearing or opting not to have children at all—have now been implicated as risk factors for the disease.

In a sense, the history of breast cancer's ascent to prominence is inseparable from the latest chapter of the female consciousness-raising movement. To battle the disease, women have united into a sisterhood, talking openly about their concerns, sharing their experiences and offering each other mutual support. They've become educated *(continued)*

(continued) medical consumers and full partners in their own care. And if there's one lesson they've learned from their struggle for equal opportunities, it's not to wait patiently by the sidelines while government legislators and policy makers make decisions on their behalf.

## Silent No More

**A** scant generation ago, breast cancer brought shame, isolation and the stigma of being less of a woman. Mastectomies were more mutilating, and victims were often viewed as sexual freaks.

NBC's Rollin remembers those dark days all too well. After her diagnosis, she reports, the discomfort of friends and colleagues was palpable. "A lot of people did not know quite what to say and avoided me," she says. Meanwhile, she was left to grapple, largely alone, with overwhelming fears and a badly bruised self-image in the aftermath of a mastectomy. While pulling the shade down in her bedroom one night, for example, she awoke to the unsettling realization that her intent was no longer to block lecherous eyes from ogling her—but, rather, "to keep the mythical Peeping Tom from throwing up." As for her gritty personal memoir of that period, it almost didn't get published. According to Rollin, the reaction of virtually every editor she approached was "Breast cancer—yuck! Who'd want to read about that?" She wrote the book anyway, largely to keep her sanity. As she explains, it served as a much-needed outlet for the terrifying, crazy feelings she was experiencing.

In fact, Rollin had more resources for coping than many of her contemporaries. One woman still shudders at how her mother, a Los Angeles housewife, reacted to her diagnosis in the early seventies. "I can still vividly recall my parents closing the curtains the day she came home from the hospital," says Christine Clifford of Edina, Minnesota. "When a neighbor walked up the front path to see my mother, she called down to me, 'Don't answer it. Pretend we're not here.'" In the three years that her mother lived, Clifford reports, she never emerged from this self-imposed exile, and her mood spiraled downward into a devastating depression.

Now in her early forties, Clifford is a two-year cancer survivor herself. But if any single advance has improved the plight of victims in the intervening years, it is the realization that they need no

longer suffer alone. Instead of shutting her door, Clifford is opening it to anyone offering support.

"You've heard of baby showers and wedding showers?" she asks. "My friends threw me a chemotherapy shower." On the eve of her first treatment, Clifford explains, they decided she needed to be distracted by something fun. No doubt a first in breast cancer social etiquette, the event was attended by sixteen of her closest friends, who brought hats as a show of solidarity in anticipation of the hair loss she could expect from the treatment. The evening featured dinner, margaritas, poker and—once the initial nervousness of guests defused—gales of laughter. "If I'd stayed home, I would have been a wreck," she

## LOOK HOW FAR WE'VE COME

*Women with breast cancer benefit from improved detection and treatment as a result of twenty-five years of advocacy. However, many of the options are still far from ideal.*

### THEN

(Early seventies)

#### INCIDENCE

82.6 women per 100,000 were diagnosed with breast cancer in 1973.

#### SURVIVAL

72 percent of patients live for five or more years.

#### MAMMOGRAPHY

Not used for routine screening until 1981.

#### DIAGNOSIS

If a lump was found, a woman waited for a surgical appointment. Her breast was cut open to expose the lump, and if it appeared cancerous, she awoke to discover a radical mastectomy had been done. Recovery from the invasive surgery was long.

#### TREATMENT

A single surgical treatment option: Halsted radical mastectomy followed by radiation if lymph nodes were involved.

#### SUPPORT GROUPS AND ORGANIZATIONS

One support group, the American Cancer Society's Reach to Recovery, offered advice and counseling from survivors on a volunteer basis.

#### RESEARCH

The National Cancer Institute's budget in 1972 for all cancer research was \$379 million (in 1972 dollars). Figures for breast cancer research alone were not being compiled.

### NOW

(Based on the most recent data)

108.3 women per 100,000 were diagnosed with breast cancer in 1993.

85 percent of patients live for five or more years.

40 to 45 percent of women fifty and older have gotten mammograms in the past three years.

Several techniques are used to evaluate lumps, from ultrasound imaging to fine-needle aspiration. When more tissue is needed, a core biopsy is done using a thin metal "straw" under local anesthesia. Tests are scheduled quickly, results are available promptly and recovery time is much reduced.

Several surgical options: Lumpectomy with radiation or modified radical mastectomy (which leaves chest muscles in place), followed by either chemotherapy or radiation if lymph nodes are involved.

The National Breast Cancer Coalition alone has more than 350 member organizations, many of which offer support groups.

The National Cancer Institute's budget for breast cancer research alone is \$332 million, with other government bodies, including the Department of Defense, providing an additional \$770,000.

says. "As it was, I had a great night in the camaraderie of my friends. It was overwhelming to feel so cared about and loved." (The epiphany of that evening also became the inspiration for a recently released book of humorous cartoons, *Not Now—I'm Having a No Hair Day*, written by Clifford in collaboration with illustrator Jack Lindstrom.)

The many more-formal support groups that have sprung up across the country in recent years offer yet another resource unknown to the isolated victims of yesterday. In addition to companionship, these groups provide something friends and family often cannot—namely, the wisdom and perspective of someone else going through the same experience.

At a recent gathering of women with advanced breast cancer near San Francisco, the liberal sprinkling of tissue boxes around the room is a measure of the gravity of their business. They have come together to discuss bereavement, loss, difficulty communicating with doctors and loved ones, their fear of dying. "We talk a lot about death because it stares us in the face every day," says Sandra Allen, fifty-two, who joined the group in 1991. "I can't tell you how many of us have died. Four women died in just four months—one of them my best friend. That's pretty heavy." Sometimes they laugh. "There's a lot of black humor in the group," she says. Often they cry. They also take care of each other. "One woman wanted fresh organic carrot juice every day," recalls Allen. "So we formed a carrot-juice brigade, and we all took turns bringing it to her."

The outcast status of earlier victims of breast cancer is particularly tragic in light of what research is revealing about group members like Allen. According to the findings of David Spiegel, M.D., a professor of psychiatry and behavioral sciences at Stanford University School of Medicine, participation in a support group offers much more than psychological benefits. In addition to being less depressed, the women in his study were living significantly longer than breast cancer patients who did not attend such a group. Though the women in each group otherwise received the same level of medical care, the typical difference in survival was eighteen months. If a new drug produced results like that, it would be hailed as a medical breakthrough.

## The New Radicals

**T**he very disease that once made women retreat in shame has also united them into a political force of enviable clout. The movement began in the early eighties as a humble grassroots campaign and was slow in getting off the ground. Even as late as 1989, for example, marshaling support for Medicare coverage of mammography was, in the words of NABCO's Langer, "a hard sell. You cannot imagine the amount of education we had to do around that issue in Congress."

Efforts to involve communities and corporations in promoting better awareness and treatment of the disease were similarly met with indifference or nervous discomfort. At the

first mention of breast cancer, CEOs often blushed or looked the other way. Bra manufacturers, when approached with the suggestion that they attach tags to their product encouraging women to do breast self-exams, shrugged off the idea as negative advertising that would only hurt sales.

Then, virtually overnight, a confluence of events conspired to push breast cancer into the forefront of public concern. The disease started to take a toll on aging baby boomers—a generation who prided themselves on their open attitude toward sexuality and their willingness to be vocal about topics off-limits to their mothers. What's more, during the sixties and seventies, they had become well schooled in political activism. With that history, they were not about to remain quiet as the disease withered their ranks. Nor had the stunning success of AIDS advocates escaped their notice. That movement, driven by educated homosexual men, demonstrated that anger could be channeled into activism that produced results. Female baby boomers heeded their lesson.

For Los Angeles-based Susan Love, M.D., a veteran of breast cancer advocacy and a former surgeon, an event in

## Voices that ROAR

**Whether you're interested in getting involved or getting information, these top organizations can tell you how. For the best books on breast cancer, see page 127.**

- National Alliance of Breast Cancer Organizations. They offer a number of free brochures, such as *Myth or Fact?* and *Facts About Breast Cancer in the USA*. 800-719-9154.
- National Cancer Institute. Information, referrals and brochures, such as *Questions to Ask Your Doctor About Breast Cancer*. 800-4-CANCER (800-422-6237).
- Susan G. Komen Breast Cancer Foundation National Helpline. 800-I'M AWARE (800-462-9273).
- Y-ME offers information and counseling and runs a wig and prosthesis bank for women in need. Available twenty-four hours a day. 800-221-2141.

June 1990 signaled a critical turning point in attitudes toward the disease. Standing before an audience of middle-aged women in Salt Lake City during a promotional tour for her new book, *Dr. Susan Love's Breast Book*, she decided to leaven the somber mood in the auditorium with a wisecrack. To shake politicians into doing something about breast cancer, "Maybe," she quipped, "we should all march topless on Washington." Afterward, a stream of mostly older, conservatively dressed women flooded the podium wanting to know, "When do we march?" At that instant, says Love, "I knew that American women were ready to make a lot of noise about breast cancer."

And that's just what they did. By the fall of 1991, the newly formed National Breast Cancer Coalition set up shop in Washington, D.C., to orchestrate a coordinated political campaign representing the interests of more than twenty major breast cancer organizations across the country. Today there are more than 350 major organizations. Advocates began bombarding their elected representatives with demands for increased spending on research. Meanwhile, extravagant publicity and fund-raising events were launched. In the largest show of the movement's strength yet, some 30,000 activists gathered last June at the Capitol Building to participate in the Susan G. Komen Breast Cancer Foundation's "Race for the Cure." The relentless pressure on Congress paid off: In just the last six years, the National Cancer Institute's (continued on page 126)

## Breast Cancer

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budget for breast cancer research jumped from \$92.7 million to a generous \$332 million, with other government bodies recently kicking in an additional \$770,000. (In comparison, the NCI spends \$123 million on lung cancer, the leading cause of cancer deaths in both women and men.)

## Patient Power

**Y**et another spin-off of activism has been the emergence of a new, more empowered breed of patient. Nancy Brinker, who founded the Susan G. Komen Breast Cancer Foundation in memory of a sister who died of the disease in 1980, recalls with deep remorse the price women once paid for entrusting responsibility for their health to Marcus Welby-type authority figures. "Susan grew up just before baby boomers, at a time when you were in the hands of your family physician," she says. "She was a woman of her times and wanted to be treated in her community." Eventually

Almost a decade later, at age thirty-seven, Katzke herself developed breast cancer—and she wasn't much happier with her medical care. A breast cancer specialist assured her the lump in her chest was benign and only agreed to perform a biopsy a year later at her insistence—after treating her, as she puts it, "like a crazy hypochondriac."

When the test confirmed her worst fear, Katzke responded in a radically different way than her mother had—she took charge of her life. She immediately fired her doctor and launched into research, reading everything she could find about breast cancer. With her medical slides and reports in hand, she interviewed specialists at several leading hospitals, eventually settling on a team of female doctors at Memorial Sloan-Kettering in Manhattan, a top-flight center for cancer therapy. Today, she credits this hand-picked group of professionals for playing a pivotal role in her recent celebration of four years cancer-free.

And that's not all. She is now suing her former doctor for malpractice. "That's another huge difference between my generation and my mother's," says Katzke. "We're not willing to gloss over serious mistakes."

developing breast cancer, have been less responsive to the siren's blare of the baby-boomer-led activist movement. According to one recent survey, for example, only 40 percent of women over sixty-five comply with the American Cancer Society's mammography screening guidelines, as compared to 52 percent of women in their forties. Those guidelines still recommend screening for women in their forties every one to two years, despite recent controversy on the topic. Some studies have shown that minority women, who die from the disease in disproportionate numbers, have been less likely to seek or receive screening services and timely treatment. Poverty, misinformation and limited access to health providers are just some of the barriers that may be blocking these groups from getting better care. Most disheartening of all, medical advances have lagged far behind the progress achieved on the sociopolitical front. State-of-the-art therapy is still often brutal and ineffective, leading breast cancer activists to brand it as "slash, poison and burn."

Yet, for all these challenges, few would dispute that victims of the disease are far better off today than a decade ago. With emotional support, survivors are living better—and longer. Thanks to increased public awareness of the importance of mammography, more cases are now being caught at an earlier, more-treatable stage—a factor that some epidemiologists believe may be contributing to a recent decline

More cases of breast cancer are now being caught at an earlier, more-treatable stage

ravaged by the disease, Komen finally traveled from her home in Peoria, Illinois, to the M.D. Anderson Cancer Center, in Houston, for treatment by a first-rate oncologist. But by then, says Brinker, it was too late. "To this day," she says, "I'm haunted by the belief that had she sought treatment earlier at a leading medical center, she might still be alive."

Brinker's sentiments are shared by many others who lost relatives to breast cancer during that era. "My mother was diagnosed in 1980," says New York filmmaker Mary Katzke. "She went to a small-town doctor in southern Minnesota who gave her a mastectomy, told her she was cured and then, to calm her down, gave her a prescription for Valium. The cancer came back in a year and a half and had spread throughout her body."

Indeed, a spate of recent litigation supports her contention: Breast cancer cases are now the most common malpractice suits. Between 1985 and 1993, 93 percent of those suits were filed by women aged fifty and younger, according to the Physician Insurers Association of America. And the majority of the cases were filed for a delay in diagnosis. The average payment in a suit during that time was more than \$190,000.

## The Long Road Ahead

**O**f course, not all women today are well informed about the disease, let alone empowered patients or political trailblazers in the crusade for a cure. Older women, the very group at gravest peril of

in the disease's death toll for the first time since the fifties. The new wave of activism is also generating a windfall of money for research at a time when advances in the molecular understanding of the disease offer the best prospects yet of a significant breakthrough in treatment. And while no one is shouting "hooray" about the progress, women can at least take heart that society's response to breast cancer is no longer "yuck!" or "hush!" ●

Photos, from page 46  
From left: top row, Kristina Bowman, Eric Pendzich/Rex USA, Globe Photos, Nils Jorgensen/Rex USA, Kristina Bowman, John Barrett/Globe Photos (2); middle row, Courtesy of Nancy Brinker, Kristina Bowman, Lisa Rose/Globe Photos, Donald Sanders/Globe Photos, Globe Photos, Michael Ferguson/Globe Photos, Kristina Bowman, Globe Photos, Rex USA Ltd., Kristina Bowman; bottom row, James M. Kelly/Globe Photos, Kristina Bowman, Henry McGee/Globe Photos, Andrea Renault/Globe Photos (2), Milan Ryba/Globe Photos, Kristina Bowman (2), Steve Daniels/Alpha/Globe Photos.