



## The Marketing of Breast Cancer

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Judy Brady has little use for the limelight. Yet, as someone with a lot on her mind, she has much to say about what she terms "the marketing of breast cancer." One of the worst examples, she says, is the Dallas-based Susan G. Komen Foundation and its annual fundraiser, the 5K Race for the Cure.

Now held year-round in 110 U.S. cities and abroad, the festivities offend Brady and the group Toxic Links Coalition. The races, they say, merely focus women on finding a medical cure for breast cancer, and away from environmental conditions causing it, the problems of the uninsured, and political influence of corporations over the average patient.

To drive this point home, Brady and the coalition have, since 1994, helped organize a vocal and visible presence most years at Komen's San Francisco race.

Sometimes leafleting, and sometimes holding up hand-painted signs and banners, they always face stiff competition from the typically uplifting and euphoric Race atmosphere. Up to 1 million participants in 2000 alone were greeted as they crossed the finish line with live music, inspirational speakers and acres of colorfully adorned corporate booths. Pink, the chosen color of the international breast cancer movement, is everywhere, on hats, T-shirts and ribbons. A sense of community and camaraderie pervades the celebration by hundreds, sometimes thousands, of breast cancer survivors and friends of survivors.

"What's missing is the truth," wrote Brady in a Spring 2001 newsletter article for the Women's Cancer Resource Center, a support services center located in Berkeley, Calif. "There's no talk about prevention, except, in terms of lifestyle, your diet for instance. No talk about ways to grow food more safely. No talk about how to curb industrial carcinogens. No talk about contaminated water or global warming."

"I really don't think environmental causes of cancer are acknowledged enough," said Dr. C.W. Jameson of the U.S. National Institutes of Health. "It warrants attention so people can make better, more informed choices, as to where they live or what professions they work in," said Jameson, the director of a biennial report on cancer-causing agents published by the Institute of Environmental Sciences.

Measuring these carcinogenic agents remains difficult despite recent gains. "Measuring levels of contaminants in the environment is getting better," says Dr. Michael McGeehin, director of the CDC National Center for Environmental Health. But proving the correlation between toxins and cancer can take decades from the time of exposure to the time a tumor might develop, he said.

Brady and the coalition are persistent in their message, yet the circle it travels in

remains small, especially when compared with that of the Komen Foundation and its founder, Nancy G. Brinker. Now the U.S. Ambassador to Hungary, Brinker is the E.F. Hutton of the breast cancer world -- when she speaks anyone who's anyone listens.

Brinker relies on the blockbuster PR value of the 5K Race for the Cure. The year-round calendar of cancer walks that draw grief-stricken yet hopeful patients and their loved ones, along with a fawning media, preserve Brinker and her group's image as being on the side of the average American woman tragically afflicted with breast cancer.

So most people would be shocked to find that the Komen Foundation helped block a meaningful Patients Bill of Rights for the women it has purported to serve since the group began in 1982.

Despite proclaiming herself before a 2001 Congressional panel as a "patient advocate for the past 20 years," demanding access to the best possible medical care for all breast cancer patients, Federal Election Commission records show the Komen Foundation and its allies lobbied against the consumer-friendly version of the Patients Bill of Rights in 1999, 2000 and 2001. Brinker then trumpeted old friend George W. Bush in August 2001 for backing a "strong" Patients' Bill of Rights, while most patient advocates felt betrayed.

Brinker's support of Bush should come as no surprise, since Bush nominated Nancy Brinker for a U.S. Ambassador post just less than one business quarter earlier, at the end of May 2001. The President also no doubt helped toast Brinker's Congressional approval for the Hungary position on Aug. 3, 2001, less than 24 hours after the House version of the Patients' Bill of Rights, dubbed "the HMO bill of rights" by critics, passed on Aug. 2, 2001.

### **The Left And Right of the Patients Bill of Rights**

Spiraling health care costs during the 1980s pushed the issue of patients' rights front and center during the 1992 presidential election. President Clinton tried unsuccessfully to increase coverage for the uninsured and to pass patient-protection legislation. "Since then, managed care reform has been resuscitated time and again on Capitol Hill without much success," according to the Center for Responsive Politics.

In 1999, 2000 and 2001, dramatically different versions of the Patients' Bill of Rights were introduced. Critics say that both versions do little to provide universal coverage for the tens of millions of uninsured. "They do not change the perverse incentives that pit economic interests of managed care companies and employers against the health needs of patients, and they do not reduce the huge overhead expenses, many of which are directed toward limiting services," wrote the former editor of *The New England Journal of Medicine*, Marcia Angell, in a *New York Times* Op-ed piece.

Patient protections proposed in the 2001 Democrat-dominated Senate bill (S. 1052), and the Republican-dominated House bill (H.R. 2563) are nearly identical, but the means of enforcing those rights are a sore spot for both parties. Backers of the Democrat version said a patient's right to appeal an HMO decision was weakened under the House bill because the HMOs control who does the review. Republicans

also insist that patients, after exhausting all appeals, head to federal court instead of state court where damage awards tend to be higher. The GOP-backed bill caps damages at \$1.5 million, compared to a \$5 million cap on the Democrat side. The legislation also blocks class action lawsuits.

### **Lobbying Largesse**

It's no accident the Komen side favors the Republicans. A July 12, 2001 agreement between the President and five companies to run a Medicare prescription discount card program for Medicare patients, included a company called Caremark Rx where Nancy Brinker was on the board of directors, according to financial records. Another vendor, Merck-Medco, is one of the many drug companies found in the Komen investment portfolio. (Nancy Brinker resigned all board seats, including Komen, when she was appointed). If approved, the discount cards would provide up to a 10 percent discount on brand-name drugs.

Meanwhile, Democrats called the whole discount card idea "laughable, utterly superficial," according to press reports, since the cards are already widely available and do little to resolve soaring prescription costs, and even costlier medical treatments.

The Komen group relies on longtime Washington lobbyist, Rae F. Evans, a self-described "corporate strategist" with little experience or interest in grassroots advocacy, who also doubles as lobbyist for Nancy Brinker's husband, restaurant magnate and polo champion Norman Brinker, of Brinker International. Norman Brinker made his fortune off restaurants such as Steak & Ale, Chili's, and Bennigan's, and has sat on the Haggar Corporation's board of directors -- along with Rae Evans -- since 1994.

Also on board for Komen's Patient Bill of Rights efforts is Akin-Gump, the fourth largest lobbying firm in the country, whose roster reads like a who's who of anti-health care reformers. Akin-Gump has direct links to the Health Benefits Coalition, industry's leading PAC in the fight to stop a Patients Bill of Rights that would boost patients' rights over their health plans.

This 30-member coalition of insurers, automakers, restaurants and other powerful trade groups presented a united front before Congress, spending millions on lobbying and advertising.

Akin & Gump clients during 1998, 1999 and 2000 included HBC members Cigna Corporation and New York Life Insurance along with Brinker-backed National Restaurant Association, according to FEC records. A&G also boasts a number of insurers, automakers and pharmaceutical firms as clients.

For his part, Norman Brinker, a longtime Komen board member, was a bitter foe of a meaningful Patients' Bill of Rights, through the efforts of both Evans' and the National Restaurant Association. This "other" NRA continually topped anti-PBR lobbying rosters, according to FEC records.

### **Patient Advocates or "Bush Pioneers?"**

Through the years, the Brinkers helped deliver the state of Texas to George W.

Bush, for the governor's seat and then the Presidency. Their phenomenal fund-raising skills earned them the moniker of "Bush Pioneers," followed up with committee positions for the Bush Inaugural Ball, which requires a minimum \$25,000 donation. On her own steam, Nancy Brinker lists nearly \$256,000 in Bush and Republican Party donations, from Bush gubernatorial races, GOP hard and soft money, and federal PAC hard money, according to FEC records.

Rae Evans likewise donated \$500 to the Bush for President Campaign in 1999. The result is that lobbyists from Evans & Black and Akin & Gump go in the doors of elected officials as important campaign contributors, not as mere constituents.

Not surprisingly, the Komen Foundation has owned \$162,843 in Brinker International stock during 2000, the only year for which records are available. The Foundation also owns stock in several pharmaceutical companies and in General Electric, one of the largest makers of mammogram machines in the world.

At 1998 Food and Drug Administration hearings the Komen Foundation was the only national breast cancer group to endorse the cancer treatment drug tamoxifen as a prevention device for healthy but high-risk women, despite vehement opposition by most other breast cancer groups. Its maker, AstraZeneca, has long been a Komen booster, making educational grants to Komen and having a visible presence at the Race For the Cure. And in 2000, the parent company Zeneca Inc., employed Multinational Business Services, the lobbyist for the anti-PBR group Health Benefits Coalition.

Tamoxifen is one of the most widely used and successful breast cancer treatments today, but groups such as the National Women's Health Network, Breast Cancer Action, Medical Consumers Union and San Francisco activist Marilyn McGregor all issued critical statements at the hearing against approving it to prevent breast cancer. They testified about the drug's troubling links to uterine cancer and the FDA's questionable criteria used to define a woman as high-risk.

Only slightly less surprising is the half-million dollars' worth of stock Nancy Brinker owns in U.S. Oncology, a chain of for-profit treatment centers (on whose board she sat at least from 1999 through 2001, according to company records). U.S. Oncology's lobbying firm of Rose & Hefling is a lobbyist for the Philip Morris tobacco company, according to FEC records. Another lobbyist for U.S. Oncology in 2000, Alison McSlarrow of McSlarrow Consulting, is former Deputy Chief of Staff to U.S. Senate Majority Leader Trent Lott (R-Miss.) -- a chief architect of the pro-HMO version of the Patients Bill of Rights.

### **View from the Trenches**

The Komen group's stock portfolios and cozy relationships with Republican leadership set them apart from most breast cancer patient groups. Even the Beltway insiders at the National Breast Cancer Coalition (NBCC), who played a major role in creating the national research and early screening agenda that sprung up nearly overnight beginning in the early 1990s, are austere in comparison. So when the Patients Bill of Rights compromise bill was announced, the NBCC, among many others, was appalled.

"Late at night, and behind closed doors," read the Coalition's August 2001 press

release, "members of Congress rewrote what would have been a strong and enforceable Patients' Bill of Rights, turning it into a sham for patients while continuing to protect HMOs."

According to the same Coalition statement, "The 'compromise' that members of Congress agreed to is worse than current law -- it stacks the deck against patients and inappropriately turns external review into judge and jury. Finally, this sham of a Patients' Bill of Rights makes a cause of action in state court tougher for patients, but easier for HMO's."

"Any corporate ties to a cancer-related industry raises huge credibility issues for a group that is trying to influence public policy," says Sharon Batt, author of a seminal book on the movement, "Patient No More: The Politics of Breast Cancer," and current Chair of Women's Health and the Environment at Canada's Dalhousie University.

"Sitting on corporate boards and organizations that have vested interests in cancer policies is an even higher level of conflict than taking funds: a board member is expected to promote the interests of that corporation," said Batt, who also spoke against tamoxifen at the 1998 FDA hearing.

"Even the NBCC takes money from the pharmaceutical industry, but I doubt (its leaders) sit on corporate boards," a fact confirmed by an NBCC spokeswoman in a recent interview.

San Francisco-based Breast Cancer Action goes one step farther, refusing all donations from corporations that make money off breast cancer such as pharmaceutical companies, tobacco and pesticide manufacturers, and cancer treatment facilities. BCA also launched a campaign to expose similar sponsorship ties inherent in the Avon cosmetic company's fund raising run.

Explained BCA's executive director Barbara Brenner, "With the growing effort by corporations to look like 'good guys' by supporting cancer organizations, it is difficult, if not impossible, to know whether an advocacy organization's positions are based on well thought out policies or on who's paying the bills."

Batt finds Brinker "eerily reminiscent" of an earlier so-called cancer activist, Mary Lasker. "Her husband, the advertising executive Albert Lasker, created the famous cigarette ad, 'Reach for a Lucky Instead of a Sweet.' In the 1940s through the 1960s, Lasker used her business and social connections to transform the American Cancer Society from a small, local charity into the world's richest, most powerful health charity. The ACS became a voice for policies that have made cancer research and early detection into lucrative business ventures with little connection to the welfare of patients or to breast cancer prevention. The Komen Foundation is a reincarnation of the ACS, but specific to breast cancer."

Batt said that one of the dangers of Komen's success is that only messages that don't threaten or embarrass corporations or the Republican Party, get through to the media and Congress.

During the 1990s for example, she said, the NBCC and smaller organizations may have convinced the National Cancer Institute and other government policy makers

to begin addressing the health concerns of a more diverse group of women: ethnic minorities, lesbians and the poor. But the power brokers in government and the corporate world still listen most readily to the messages publicized by the high-profile Race for the Cure or, another corporate and Komen darling, the National Breast Cancer Awareness Month each October.

"The problem with those (awareness) programs," said Batt, "is that, unless you also fund treatment for those same women, you don't help them by detecting their cancers earlier; and you perpetuate the emphasis on mammography screening, rather than prevention, better treatment and equitable care."

But it's an uphill battle, she said. "For one thing, the Komen Foundation has had more money. For another they carry friendly, reassuring messages through the media and their own programs, a phenomenon I like to term the 'Rosy Filter,' meaning the public is spoon-fed through a rose-colored lens stories of women waging a heroic battle against the disease, or the newest 'magic bullet.' Yet little light is shed on insurance costs, the environment or conflicts of interest."

Nancy Brinker has reached large audiences by billing herself as an objective patient advocate, and signing as a "medical speaker" for Barber & Associates, a booking agency that handles broadcasters and television experts such as ABC's Dr. Nancy Snyderman, Dr. Bernie Siegel, Dr. Joyce Brothers, and Jane Brody of the New York Times.

### **The Environmental Disconnect**

One topic you'll never catch either of the Brinkers mentioning is the need for a cleaner environment. That might be because the international petrochemical giant Occidental Corp., big Komen boosters and the same folks who brought us Love Canal, donates 4,000 square feet of "glass and marble offices" to Komen on the premises of Occidental's Dallas headquarters.

The petrochemical industry, including Occidental, successfully lobbied in 2000 and 2001 for looser EPA air, water and chemical regulations at the same time government researchers reported auto and industrial emissions caused cancer. In March 2002 alone, the EPA approved a two-year delay of the Clean Air Act rules that would cut toxic emissions from 80,000 industrial sources.

Officially, the Komen group is pro-environment, and joined with a national coalition of cancer and women's groups in late 1999 to demand research on the links between breast cancer and environmental toxins. However, a subsequent Congressional bill, the Breast Cancer and Environmental Research Act, went nowhere fast when it was introduced in May 2001. Komen's lobbyists made little or no effort to fight for the bill or the concepts behind it, according to mid-year 2001 lobbying records filed by Evans & Black and Akin & Gump. Black, along with many Occidental officials, sat in with Brinker, on the Bush Inaugural Committee.

Coincidentally, Occidental lobbyists also spent time in 2001 on the House version of the Patients Bill of Rights. Charles Black, one of Occidental's lobbyists, spouse of Evans & Black's Judy Black, and a leading Republican strategist, is also a consistent lobbyist for Brinker International. Charles Black is a board member of the American Conservative Union, a group that defines pharmaceutical price controls as "a bitter

pill for American consumers," and "beating up on the pharmaceutical industry." And Black, along with many Occidental officials, sat in with Nancy Brinker on the Bush inaugural committee.

### **The American Way?**

Komen's political biases and conflicts of interest evade public scrutiny primarily because lobbyists and nonprofits like Komen are required to tell us only a few details of their work. As a Washington consumer group official quipped, "Politicians don't even want to admit talking to lobbyists much less saying which ones they spoke with, or why."

In 2001, for example, Evans & Black listed both Democrat and Republican versions of the Patients Bill of Rights in its disclosure reports; its 1999 and 2000 reports were right out front by listing the Republican version. Likewise, Akin & Gump's 2001 reports show it lobbied "pertaining to" the Senate's more liberal version. As a result it's impossible to prove which version it was lobbying for. But it's also a foregone conclusion, given the Komen's characterization of the GOP-ruled version as "strong," the close and longstanding ties with President Bush and the Republican party, and its vested interests with industry.

Komen lobbyist Rae F. Evans said that she refused to talk about which legislators were approached about the Patients' Bill of Rights and their position on it because it would be "unethical." Moreover, she said, "It's only a problem for journalists."

Komen's freewheeling lobbying is possible because of a little-known exemption written into the U.S. tax code a quarter century ago. In 1976, the nation's nonprofit organizations were granted the right to hire, or go toe-to-toe with, professional lobbyists on Capitol Hill, while maintaining tax-exempt status.

Nonprofits can spend 20 percent of the first \$500,000 of annual expenditures on lobbying, 15 percent of the next half-million, and so forth, up to \$1 million per year, according to an IRS fact sheet. Spent this way, the entire amount is deductible, allowing the Komen Foundation to emphatically state -- as it has whenever asked -- that it spends "zero dollars" on lobbying.

Can stock ownership, directors' seats, campaign contributions and longstanding business relationships result in any tangible effects on a nonprofit's mission? At best, it's tricky to prove any material conflict of interest, and even a cancer patient-advocacy organization is allowed by law to be right-wing, well-connected and pro-industry. According to Bennett Weiner, Chief Operating Officer of the Better Business Bureau Wise Giving Alliance, a national charity rating organization, "As long as they fulfill what's described in their mission statement."

In Komen's case, that mission would be to "stop cancer as a life-threatening disease through research, detection and education," according to Komen's statements.

But, Weiner continued, it's wrong for Komen's literature, Web site, and public statements to feature a central figure like Nancy Brinker -- or Norman Brinker for that matter -- while omitting relevant parts of their lives such as seats on boards of private cancer treatment corporations, stock interests, lobbying ties or their political activism as GOP darlings. Weiner said, "If a charity is making recommendations to

the public regarding health care among other things, and if they have ties to the industry, then the public needs to be able to objectively use that information."

As it stands now, even the watered-down Patients' Bill of Rights is on life support, after President Bush refused to sign it over lingering liability limitations, unknown at press time, according to a spokesman for U.S. Sen. Edward Kennedy (D-Mass), co-sponsor of the Senate's Bipartisan Patient Protection Act. Quiet negotiations with the President still continue. In late June 2002, U.S. Sen. John Edwards (D-North Carolina), released a statement saying, "(I) remain optimistic that negotiations with the White House will produce agreement on meaningful patient protection that Congress could pass this year."

The Foundation denies that it spends money to lobby, and denies that it is solely aligned with the Republican health care and environmental agendas. In a September 2001 letter in response to questions for this article, a Komen spokeswoman defends Norman Brinker as a devoted "volunteer." The Foundation even seemed to distance itself from Nancy Brinker by citing her new post overseas.

Full disclosure could be slow in coming, given the vast tangle of political, business and personal alliances involved. Even a spokesperson in Sen. Edwards office, a staunch defender of a liberal Patients' Bill of Rights, recalls the Komen Foundation as one of his biggest clients at Fleishman-Hillard, the sixth largest PR firm in the world.

As Judy Brady points out, the Komen Foundation, and the Brinkers in particular, represent the systemic corruption of business as usual in a corporate-dominated society. "It would be a mistake to demonize the Komen Foundation," Brady says. "They have the best of intentions and I truly believe that they think they are doing good -- with a capital G.

"What they don't see is that 'business as usual' is why we have cancer."

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