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Statement of Dr. Samuel Broder

National Cancer Institute

Good morning, Mr. Chairman, and Members of the subcommittee. I am Dr. Samuel Broder, Director of the National Cancer Institute (NCI). Thank you for the opportunity to appear before you today to discuss the NCI's position, and the scientific basis for that position, on screening for breast and cervical cancers, two areas critical to women's health.

Cancer is the second leading cause of death among women in the United States. In 1994, about 250,000 women will die of all cancers combined, about 46,000 dying of breast cancer. It is the most common cause of death from any cause in women aged 40-44. The incidence of breast cancer is increasing and has been increasing since 1973. Although there are now slight decreases, the situation is dire. Since 1987, breast cancer incidence, fortunately, has reached a plateau and has actually decreased slightly. Some of the increase in incidence over the 1980s is attributed to increased detection due to mammography; the longer term increase is less well understood. We do not believe that the increase can be fully understood without more basic research.

Turning to cervical cancer, in 1993, 13,500 American women were diagnosed with this disease and 4,400 died. Fortunately, the incidence of invasive cervical cancer and the death rate have decreased in the United States over the past several years, because the Pap screening test can detect the pre-malignant or <u>in situ</u> stage. This early stage can be effectively treated, and yet even here, there are problems as sometimes the cells captured are

not the atypical ones, and beyond that some women are not being screened and among those who are screened some are not being treated. The Pap test, developed by George Papanicolaou, has been used since the 1940's. This test, like others, has limitations. Sometimes the cells are imperfectly gathered, nor are all tests read and interpreted accurately. NCI has worked to improve the reading of the Pap test and has introduced the "Bethesda system" which has clarified and standardized reporting. But the Pap test is an excellent tool, even when its limitations are taken into account. Here there is good progress from basic research to report on a vaccine against cervical cancer. The ability to create such a vaccine grew out of years of research on viral carcinogenesis.

The issue of mammography is an area of intense polarization between various groups at this time. The polarization has occurred not because of fundamental differences--we all share the concern that women are dying of breast cancer--but because we have different perspectives on this problem. The key question before us all is how to go about reducing the devastating toll of breast cancer and cervical cancer. The NCI is a science institution, a biomedical research institution committed to generating the knowledge needed to reduce the suffering and death from cancer. While at times there have been bursts of enthusiasm for research advances that promised to cure cancer, we all recognize that cancer has not been cured. Today, there are exciting developments on many fronts, particularly in basic research, but as we discuss these achievements, we must acknowledge that cancer poses an awesome research and therapeutic challenge. We must have no illusions on this point.

As a scientific organization, we know that opinions and practices may require adjustments or fundamental changes as we learn more facts about normal biology, more about the cancer cell and have more opportunity to assess diagnostic tools and treatments. At the same time, we have seen that yesterday's "incurable and fatal" disease can be tomorrow's medical triumph, and that a disease that terrorizes one generation can be only dimly remembered by the next generation. Two principles need to guide us wherever possible: the consensus of scientific peer groups and clinical trials as the instrument for consensus wherever possible.

Each of us has a role to play in this enormously important effort to save the lives of American women. I believe that NCI's role is the generation of knowledge, the sharing of that knowledge and translation of scientific knowledge into clinical reality at the community level. We could not advocate a treatment being continued if followup clinical trials showed that its benefits were initially overstated, that in truth, it brought no reduction in deaths in the real world. By the same rules, we must adhere to what we have learned about the value of mammography for women in various age groups. After a process of scientific evaluation, after extensive review of data from a number of clinical trials, after internal and external debate, and most important of all, after seeking the input and advice of our most respected non-governmental experts, we have an obligation to share the results of this process with the women of America. We owe it to them to provide the most accurate information available about screening and treatment of breast and cervical cancer at a point in time. In the case of mammography, a routine program of screening will definitely save lives. This technology has been proven in randomized clinical trials for women over age 50, and moreover there is a

clear and unmistakable consensus on this point. For women under 50, neither condition applies at this time.

One point must be emphasized: this discussion does not address diagnostic mammography, where a doctor and woman are joined in following symptoms or other indications, such as a lump, pain, or swelling, of a possible malignancy. That is a different situation entirely. Here, in this discussion, we are focusing on the concept of screening in women who are free from known signs or symptoms.

It is important to note that mammography is only one of several technologies being examined by NCI. For example, a large clinical trial, the Prostate, Lung, Colorectal, and Ovarian (PLCO) trial, has begun to evaluate screening tests in these cancers. This study will assess the predictive value of the widely used test for prostate specific antigen (PSA) and less used technology such as ultrasound, CA 125 or flexible sigmoidoscopy. In women, for instance, the study is designed to determine if screening with pelvic examination plus serum CA 125 and transvaginal ultrasound can reduce deaths from ovarian cancer. Thus, for tests such as PSA, we are not recommending its adoption as a routine screening tool until clinical trials and a scientific consensus permit us to do so.

The rank-and-file scientists who work in the National Cancer Program, both intramural and extramural, are superb and they are a dedicated group of men and women. They are working to find new ways to prevent, detect and treat breast and cervical cancer. NCI supports

research aimed at locating important genes and genetic processes in breast cancer. Research is being carried out on specific inherited gene abnormalities and certain familial predispositions to breast cancer including benign proliferative breast disease; the Li-Fraumeni syndrome, in which family members inherit a mutation in the p53 tumor suppressor gene, located on the short arm of chromosome 17; and early-onset familial breast cancer, linked to abnormalities also on chromosome 17 referred to as Breast Cancer-1 or BRCA-1.

Collaborations with the National Center for Human Genome Research are designed to elucidate genetic information about breast cancer. On December 2, 1993, we were pleased to announce the finding of a gene for colon cancer that also appears to play a role in ovarian, uterine and several other cancers. When genes are found, tests can be developed to show which women are at risk. Sometimes the genetic discovery will aid in developing vaccines or new prevention strategies.

At times, conditions not typically thought to fall within a definition of women's health are of surpassing importance. Thus, the gene for Ataxia-Telangiectasia when carried by an otherwise normal woman can predispose her to radiation damage and breast cancer. As carcinogenesis studies progress, this information could be used to counsel women at high risk to avoid certain environmental exposures and to undertake individualized programs of screening and prevention. We are looking specifically at breast cancer and the interaction of various occupational and environmental hazards in the NCI Long Island Breast Cancer Study

Project. This will provide information not only for New Yorkers, but for women everywhere.

Genetic discoveries will yield new molecular tests that might have high specificity. We are not waiting for these events to occur. We are working to refine our knowledge of the tools we have, including mammography and Pap tests. We are encouraging the development of new digital mammography techniques, which would also allow transmittal of images for consultation or diagnosis by specialists. New imaging techniques are being used to more accurately guide biopsies and surgery. Other methods are borrowing from space or defense department technology. None of us is content. All of us know that cancer is the second leading cause of death among women in the United States and we know the suffering caused by this disease.

NCI research has shown that the impact of cancer in general on minority and underserved populations is disproportionately great. This impact is certainly felt in breast and cervical cancer incidence and mortality rates. Even where incidence rates are lower for African-American women than for white women, as is the case with breast cancer in women ages 40 and over, the mortality rates of African-American women are higher. Cervical cancer incidence rates for African-American women are about twice the rates for white women, and mortality rates are about three times the rates for white women.

Screening and access to screening are only one aspect of this very complex situation, one that tangles economic issues, educational issues, access to screening and diagnosis and access to treatment with many other variables including genetic and environmental ones. Mammography has seemed to be a successful way to introduce some underserved women into the medical system. In some ways, it has become a metaphor for concern about breast cancer, even a way a woman could express her determination to protect her health. But mammography was never designed to do all that--it is a medical tool. Mammography was designed to screen for breast cancer and where it is efficient and there are other benefits, that is all to the good. Thus, for women over 50, mammography is an established screening tool. But there is extreme disagreement concerning women under age 50. Therefore, in this setting, we must state what we know and what we do not know.

A word about the history of NCI recommendations is in order. In 1987 the NCI developed Working Guidelines for the early detection of cervical and breast cancers. These guidelines provided the American public with a summary of the state of knowledge at the time.[1] The guidelines regarding screening mammography for breast cancer detection (which can be defined as a regularly performed mammogram for a woman with no presumptive evidence or symptoms of breast cancer) were as follows:

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[1] It is important to stress that none of these guidelines pertain to diagnostic mammography, which is performed as a result of a clinical suspicion (such as a lump or nipple discharge). In the setting of a clinical suspicion, whether because of symptoms or physical findings, mammography is generally a necessary medical tool.

♦ The screening process should begin by age forty and consist of annual clinical examination with screening mammography performed at one to two year intervals.

♦ Beginning at age fifty both clinical examination and mammography should be performed on an annual basis.

♦ Physicians should encourage women to perform monthly breast self-examinations.

At the time these guidelines were developed, evidence for screening was strongest in women ages 50-69, although the Health Insurance Plan (HIP) of Greater New York clinical trial had shown a reduction in cancer deaths due to screening in a group of young and older women all mixed together. The above guidelines were considered working guidelines with the intent to revisit them should any new information become available.

Similarly, the working guidelines for cervical cancer screening developed in 1988 are as follows:

♦ All women who are or who have been sexually active or who have reached the age of 18 years should have an annual Pap test and pelvic examination.

♦ After a woman has had three or more consecutive, satisfactory, normal annual examinations, the Pap test may be performed less frequently at the discretion of her physician.

Over the ensuing six years there has been no new information to contradict the basic meassage of the original guidelines on cervical cancer and the consensus among scientists has held firm. Over the last two to three years, however, several events have led to an ongoing re-evaluation of the breast cancer screening guidelines:

♦ First, an NCI-supported meeting entitled "Forum on Breast Cancer Screening in Older Women" was convened in April 1992. Among the recommendations was the following: "There was enough direct evidence to support a recommendation for universal screening in women sixty-five to seventy-four years of age. Because of the lack of direct evidence regarding screening efficacy and because of increasing occurrence of multiple chronic diseases in women seventy-five years of age and older, the Forum concluded that clinical judgment was necessary to weigh the relative benefits of comorbidity and screening effectiveness for the individual patient in this age group ... Regarding the interval for mammography and clinical breast examination, the Forum concluded that there was no evidence to choose one interval over another, since apparently equally effective intervals have ranged from twelve to thirty-three months."

♦ Second, the Canadian National Breast Screening Study of screening women in their forties, published in November 1992, did not show a mortality benefit ascribed to mammography after seven years of follow-up. Dr. Anthony Miller presented a preliminary analysis of this study in closed session to the Board of Scientific Counselors of the NCI's Division of Cancer Prevention and Control (DCPC) as far back as October 1991.

♦ Third, an overview analysis of five randomized screening trials conducted in Sweden in the 1970's was reported early in 1993. The study found that the largest reduction of breast cancer mortality, roughly one-third, was observed among women aged 50-69 at randomization. Among women aged 40-49 at randomization, no statistically significant difference was observed.

I would like now to briefly discuss the process by which NCI came to the specific change under discussion today, but before doing so, I want to put to rest the concern that the NCI's position is influenced by political considerations or expediency.

This process was, in one way, initiated in 1991. It was obvious that there was a need to evaluate the new information in the context of the large body of evidence which had evolved since the landmark Health Insurance Plan (HIP) study of thirty years ago. Following a pre-publication, closed briefing in the Fall of 1991 on the Canadian mammography study, NCI began planning a major international workshop of breast cancer screening that was held in

February 1993. Many of the scientists who performed the studies, as well as researchers in breast cancer screening fields, participated in this workshop. Results from all eight published randomized clinical trials of screening mammography were reviewed. At that workshop an overview analysis, a meta-analysis, was presented by New Zealand investigators of all the randomized screening trials in the world. This analysis raised questions regarding the benefit of screening women between the ages of 40-49. This workshop was open to both the press and the public. At that time, NCI provided information and resources to the media, interested voluntary, advocacy and health professional organizations, and the public, on the mammography screening studies that were being reviewed.

The final report of the workshop concluded:

- First, "The randomized trials of women ages 40-49 are consistent in showing no statistically significant benefit in mortality after 10-12 years of follow-up. .... For this age group, it is clear that in the first 5-7 years there is no reduction in mortality from breast cancer that can be attributed to screening. There is an uncertain and, if present, marginal reduction in mortality at about 10-12 years. Only one study provides information on long-term effects beyond 12 years, and more information is needed."

- Second, "For women ages 50-69, the evidence presented at the Workshop strengthens the scientific observation that screening leads to reduced breast

cancer mortality. Every study presented found a protective effect for women in this age group. .... The Swedish studies suggest that a screening mammogram as infrequent as every 33 months reduces breast cancer mortality, at least in a population with a high compliance rate and in a setting with high-quality mammography. These data raise the possibility that a screening interval of every 12 months may not be necessary in this population."

♦ Third, "Women in their 70's are a high risk group for breast cancer. The currently available clinical trial data for these women are inadequate to judge the effectiveness of screening because the numbers of women were small, the compliance was poor, and the screening episodes were too few."

The Workshop charge was to critically review and summarize the scientific evidence, not to develop guidelines per se. In response to this analysis, NCI staff began the process of reviewing our Working Guidelines in the context of the new information. NCI has a responsibility to provide accurate, clear information to the public-based on scientific evidence. This information clearly held an important public health message for all women and health care professionals.

Subsequently the following process has taken place:

♦ During the period from May through August 1993, the NCI PDQ Editorial Board, consisting of both NIH and non-NIH researchers, reviewed and endorsed Workshop results; the NCI staff developed draft guidelines/recommendations which were reviewed by the NCI Executive Committee; NCI staff also met with the American Cancer Society (ACS) to discuss principles underlying the NCI draft guidelines.

♦ In September 1993 the draft guidelines were reviewed and discussed by PHS agencies and selected participants from the February 1993 International Workshop on Breast Cancer Screening; NCI staff met with the ACS Breast Cancer Subcommittee, the National Cancer Advisory Board, and with individual members of the DCPC Board of Scientific Counselors to discuss proposed guidelines.

♦ During October 1993, NCI disseminated draft guidelines and other materials to agencies involved in earlier guidelines and voluntary advocacy groups, with a request for written comments and attendance at the upcoming October 21 meeting of the NCI DCPC Board of Scientific Counselors.

♦ On October 21, 1993, the guidelines were reviewed by the DCPC Board of Scientific Counselors, who passed a motion recommending that the existing recommendations for women 50 years and over be maintained, and that for women under age 50 NCI provide a summary of existing evidence and data and suggest that

these be discussed with each woman's physician or health care provider. In effect, the Board wanted to present the facts, without the pronouncement of a guideline.

♦ On November 22-23, 1993 the National Cancer Advisory Board passed the following motion: "Recognizing that there is controversy on the effectiveness of mammography for women under the age of 50 that calls for more research, the members of the National Cancer Advisory Board recommend that the National Cancer Institute defer action on recommending any changes in breast cancer screening guidelines at this time."

♦ On December 3, after careful consideration of the conflicting advice of scientific experts, NCI released the following statement summarizing our position on breast cancer screening:

> "There is a general consensus among experts that routine screening every 1 to 2 years with mammography and clinical breast examination can reduce breast cancer mortality by about one-third for women ages 50 and over.
>
> Experts do not agree on the role of routine screening mammography for women ages 40 to 49. To date, randomized

clinical trials have not shown a statistically significant reduction in mortality for women under the age of 50."

The process has been open and candid. We have extended our outreach to many diverse groups, both scientists and consumer advocates. We have heard from women's advocacy groups who strongly oppose the use of routine mammography in women under 50 and those who with equal force hold the opposite view. NCI has been intensively reviewing the state of the science regarding mammography screening efficacy for at least two years. After the Workshop conclusions were clear, NCI conducted surveys and focus groups with women and health care professionals to anticipate issues which might help to prepare health professionals and the public for such changes.

Results from the surveys and focus groups indicated that women clearly understand that scientific debate on health issues is sometimes unavoidable.

The NCI maintains communication with many voluntary, advocacy and health professional organizations in the areas of cancer prevention, early detection, and treatment. NCI has redoubled its efforts to stay in close communication with these organizations and to assist where possible in minimizing the confusion that often occurs when recommendations change. And yet, we sometimes must differ even while we may at the same time respect and admire those who disagree with us.

On December 3, 1993, NCI released the new mammography statement and simultaneously communicated with all its own units including the Cancer Information Service--which answers inquiries via the toll-free 1-800-4-Cancer telephone number, the National Black Leadership Initiative on Cancer, the National Hispanic Leadership Initiative on Cancer, the Appalachian Leadership Initiative on Cancer; the Cancer Centers Public Affairs Network; and the Centers for Disease Control and Prevention to determine the strategies and tools needed to convey NCI's breast cancer screening messages in light of the latest scientific review. NCI immediately began updating its own publications and developing a consumer brochure that explains the new position on breast cancer screening for women 40 and over.

The NCI Division of Cancer Prevention and Control is planning a meeting of organizations within the Public Health Service to determine how best to work together on this issue and to organize an ad hoc committee of NCI staff as a first step to develop effective strategies to educate physicians and other health care providers on the new NCI mammography statement.

Perhaps most importantly, NCI staff will continue to meet with breast cancer advocacy groups and voluntary organizations, such as the American Cancer Society (ACS), to clarify issues, identify common ground--and there is common ground--foster cooperation, and explore joint communication efforts, where this is possible.

Mr. Chairman, I welcome your interest and the interest of this Committee and the Congress in this issue. Please allow me to repeat myself: Each of us has a role to play in this

enormously important effort to save the lives of American women. This dialogue on mammography is part of the effort. NCI must generate and assess knowledge and then assist in translation of scientific knowledge into the care given at the community level. Science is not separate from life, it is our effort to understand life. NCI's recommendations must be based on scientific evidence to the greatest extent possible, and they must change as new information becomes available. Thank you, Mr. Chairman, for this opportunity to testify. I would be pleased to answer any questions you or other members of the committee may have.

- **Breast cancer is the leading cause of death for women 40-44 and the leading cause of cancer deaths in women 15-54.** Incidence of breast cancer increases with age, rising sharply after age forty. Two-thirds of all breast cancers occur in women over 50.

- **Mammography does not prevent or cure breast cancer, it can only detect it "early".** In this context, "early" means that the tumor can be there for six to ten years before it is detected by mammography.

- **Most breast irregularities are found by women themselves, yet many women do not know how to perform breast self-examination and few do so regularly.**

CONTACT :
THE NATIONAL BREAST CANCER COALITION FOR INFORMATION ON HOW TO HELP FIGHT TO END THIS EPIDEMIC

P.O. Box 66373
Washington, D.C. 20035

• BREAST CANCER FACTS

The National Breast Cancer Coalition • *a grassroots advocacy effort*

- **Breast cancer is the most common form of cancer in American women.** It rarely occurs in men. An estimated 2.6 million women in the U.S. are living with breast cancer: 1.6 million who have been diagnosed and an estimated 1 million who do not yet know they have the disease.

- **One out of nine women in the United States will develop breast cancer in her lifetime — a risk that was one out of 14, in 1960.** This year, a new case of breast cancer will be diagnosed every three minutes, and a woman will die from breast cancer every 12 minutes.

- **In 1993, approximately 182,000 new cases of breast cancer will be diagnosed and 46,000 will die from the disease.**

- **We do not know what causes breast cancer or how to cure it.** Women with breast cancer are dying at the same rate today as they did in the 1930s, and the same basic methods of treatment are being used: surgery, chemotherapy and radiation.

- **Since 1960, more than 950,000 U.S. women have died of breast cancer.** This is more than two times the number of all Americans who have died in World Wars I and II, the Korean, Vietnam and Persian Gulf Wars. Forty-eight percent of these deaths occurred in the last ten years.

- **Thirty eight percent of African American women with breast cancer will not live more than five years, and 25% of white American women with breast cancer will not live more than five years.** Forty percent of all women with breast cancer are dead within ten years.

- **Every woman is at risk for breast cancer.** The risk of developing breast cancer increases as a woman ages, if she has a family history of breast cancer, has never had children or had her first child after age 30. Most breast cancer (over 70%), however, occurs in women who have no identifiable risk factors.

▶

President William Jefferson Clinton
Remarks to the National Breast Cancer Coalition
The White House
October 18, 1993

[Recognitions]

The White House has seen more than its share of unusual gatherings and important moments since we arrived here nine months ago. But today marks a special occasion for all of us. This morning, each of us is reminded of the despair that a terrible and frightening disease has brought to our lives. But we meet also to celebrate your courage and your commitment to making the lives of women all over our nation safer and more secure.

This is an audience that is all too familiar with the grim statistics that lie behind the ravages of breast cancer. In the three minutes since I stepped up to this microphone, another American woman has been diagnosed with breast cancer. Every twelve minutes, a woman in our nation dies from it. Recent surveys have found that one in every three women does not receive basic services like mammography that can help detect breast cancer. And breast cancer will cost our nation an estimated $6 billion this year in medical bills and lost productivity.

And yet despite the proportions of this epidemic, and the best efforts of some of this nation's best scientists and doctors, we don't know what causes breast cancer. We don't know how to prevent it. And we don't know how to cure it.

What we do know is what it does -- not only to women, but to all of us.

[option: story of your mother's illness and it's impact]

The devastating effects of this illness were brought home to me most recently on a July day when Sherry Kohlenberg came to visit Hillary and me in the Oval Office. Some of you in this room knew Sherry; she was a breast cancer victim who worked with your Coalition.

In the early part of this year, Sherry had been in remission but then, in the spring, she had a relapse. She contacted us and said that, before things got worse, she wanted to

have her son, Sam, meet the President. And so she brought Sam and her husband, Larry, to visit.

Sherry was in a wheelchair that day, her husband pushing it, and Sam clinging to her leg. We spent about a half-hour together. And as they left the Oval Office, Sherry turned to Hillary and me and said: "Don't ever let anyone forget what this disease does to those who are left behind."

We told her we would not. And I am pleased this morning to be able to say to Sam and Larry -- they are with us this morning and I salute them for their courage...Let me say to all of you this morning we have not forgotten Sherry's words. And we are working hard to make it possible for all of our mothers and daughters to live in a world where breast cancer no longer numbers among their fears.

Meeting that promise will require action on all fronts in the war against breast cancer. And I can report to you today that we are moving on each of those fronts -- research, detection, delivery, and outreach.

Because we recognize that future progress against breast cancer depends on our ability to tackle new frontiers in basic research, I proposed -- in my first budget submission -- the creation of the Office of Research on Women's Health and the largest increase in funding for breast cancer research in the history of the National Institutes of Health. We have also increased funding for detection and preventive services at the Centers for Disease Control, the Food and Drug Administration and the Department of Defense. Together, it adds up to some $600 million this year alone.

As one step in coordinating our research and delivery efforts, I am pleased to announce that -- in keeping with that commitment -- Secretary Shalala will bring together groups like yours, a broad range of health professionals, and government officials to develop a national action plan for the prevention, diagnosis and treatment of breast cancer. Developing and carrying that national strategy is what these petitions that you have

delivered are all about -- and with your help, I am convinced the Secretary will succeed, and that we will all be better off as a result.

But research, as you have consistently pointed out, is not enough. We need to do everything in our power to detect this disease early and to make mammography and medical treatment available to every American woman.

I believe that our Health Security plan is going to fundamentally change the fight against breast cancer. It is a plan that -- quite frankly -- shows the signs of several strong women at work. A plan that is based on the notion that, when it comes to health care research and delivery, women must no longer be treated as second class citizens. That we must invest in prenantal care, nutrition, maternals and child health. A plan that is based on the idea that we must try and detect and prevent disease -- not just try to heal people after they fall ill.

The Health Security plan guarantees every American a comprehensive package of benefits that can never be taken away. And at the core of those benefits are a wide range of preventive benefits provided at no cost to the patient, some of which will help us take great strides in the fight against breast cancer.

Among other things, the plan covers, at no cost to the patient, routine clinician visits, where women can receive appropriate clinical breast exams and other important preventive services -- things like immunizations and Pap smears. Because we know that we can reduce deaths by making mammography widely available, the plan covers mammograms every two years -- at no cost to the patient -- for all women over 50. And for those women who are at high risk of developing breast cancer, the plan provides more frequent mammograms at any age. Let me assure you that these benefits are based on the best available scientific evidence -- and can be updated to reflect new or better studies, or recommendations like those we will soon receive after two years of hard work by the President's Special Commission on Breast Cancer.

Finally, our Health Security plan recognizes a seemingly simple but critical fact: the best care in the world doesn't do anybody any good unless you can get to it. And so our plan will offer new help to our nation's public health system....it will spread the latest technology to doctors and nurses in the smallest rural communities and our nation's inner cities....and it will allow every health professional to contribute to the best of her or his ability and training.

As you know from your effort to gather these signatures, change requires that people work together. I believe that working together, we can develop a strategy to win the war on breast cancer and create an American health care system that is grounded in equality, compassion and security. Health care that says women's health care must be given equality -- in attitude and dollars. Health care that says it's better to keep people healthy -- not only treat them after they get sick. Health care that says every one of us deserves health security, health care that is always there.

Every American brings unique experiences, skills and weapons to the battle against illness and the battle for health security. Your weapons are not the dollars and deal-making talents of the lobbyists. They are not the stethoscopes or the syringes of the doctors and nurses. They are the pen and the petition -- and the knowledge that a chorus of voices is so much more powerful than even the strongest voice singing alone.

I urge you to continue your fight, and add your voices to ours in the months ahead.

[after applause]

Now I am going to sign a proclamation that declares tomorrow, Tuesday, October 19th, National Mammography Day.

Petition to President William Jefferson Clinton to implement a Comprehensive National Strategy to End the Breast Cancer Epidemic

182,000 women in this country will be diagnosed with breast cancer this year and 46,000 women — one every 12 minutes — will die as a result of this disease. Without a comprehensive strategic plan to end this epidemic, the loss of human and financial resources to the nation , already of staggering proportions, will only escalate. Through this petition, the women of this country, and those who care about them, ask that President Clinton bring together leaders from his administration, the Congress, the scientific community, private industry and women with breast cancer and other breast cancer advocates, to put in place a comprehensive plan to end the breast cancer epidemic.

Name	Street City and State	Zip	SIGNATURE	Why You Care
				I am a: ☐ Survivor ☐ Spouse or Partner ☐ Daughter, Son ☐ Parent, Grandparent ☐ Sister, Brother ☐ Friend, Co-Worker of someone who has been affected by this disease, or ☐ a person concerned about this epidemic.
Add your personal message here:				
				I am a: ☐ Survivor ☐ Spouse or Partner ☐ Daughter, Son ☐ Parent, Grandparent ☐ Sister, Brother ☐ Friend, Co-Worker of someone who has been affected by this disease, or ☐ a person concerned about this epidemic.
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Add your personal message here:				

Return by October 1, 1993 to the National Breast Cancer Coalition
P.O. Box 6673, Washington, DC 20035

Petition to President William Jefferson Clinton to implement a Comprehensive National Strategy to End the Breast Cancer Epidemic

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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 breathtaking 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 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

Breast Cancer Research
A Special Report

News editor: Colin Norman
Copy editor: Troy P. Gately
Designer: Diana DeFrancesco

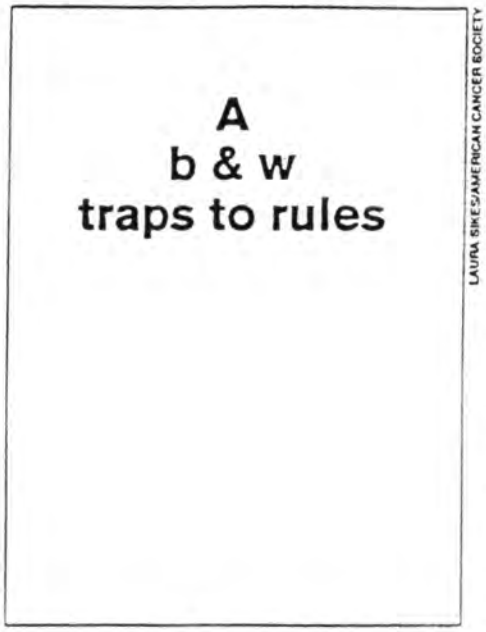
Center in Seattle, Darcy Spicer of the University of Southern California, and Graham Colditz of Harvard. To no one's surprise, they revealed that their work could use additional funding. NBCC came up with a proposed 1993 *increase* for NCI of $300 million, spelling out categories into which it should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

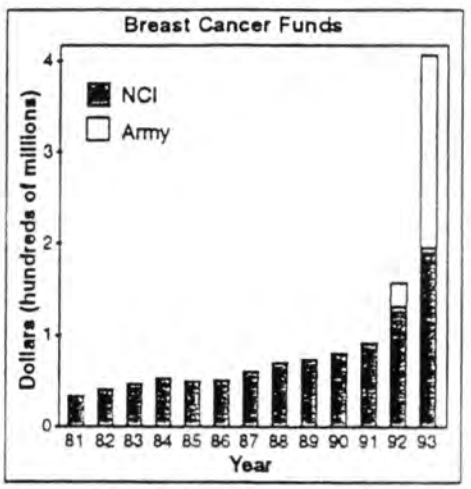
As a result, the Army now has a new mission and $210 million to spend on it. Because it doesn't have a peer-review system comparable to NIH's, the U.S. Army Medical Research and Development Command (USAMRDC) is asking for some help from the Institute of Medicine (IOM). General Richard Travis, USAMRDC's 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-payoff" 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



LAURA SIKES/AMERICAN CANCER SOCIETY



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

The debate over the screening tests is fiercer than ever. And the age group that stands to benefit the most isn't getting the message.
By Jeanmarie Marshall

WHO NEEDS A MAMMOGRAM?

In all the controversy surrounding mammography and breast cancer, one fact is unassailable: More than 75 percent of breast-cancer cases occur in women older than 50, who have the most to gain from regular screening mammograms. Unfortunately, many of these women aren't getting them: According to a recent poll, only half have had one or more mammograms. And a recent study funded by the American Cancer Society revealed that many older women don't think they need the test. "We're not getting the message across that mammography is a good tool for them," says Susan Love, director of the UCLA Breast Center.

Part of the problem is that the models in ads touting mammograms have been conspicuously youthful. "Breast cancer becomes more common the older you are," says Love, "but you'd never know it from the way the disease is depicted in the media, including the public service ads." This month the American Cancer Society is cosponsoring the first-ever public service campaign that encourages women older than 60 to get mammograms; actress Anne Bancroft will provide the voice-over for the TV and radio spots.

The ACS and the National Cancer Institute recommend that women have mammograms every one to two years between ages 40 and 49, and every year after age 50. (They also recommend annual clinical exams and monthly self-exams.) But the recommendation for younger women is under increasing attack. Susan Love points out that "there's no good randomized data to show mammograms are useful as screening tests in women under fifty." The American College of Surgeons was asked to endorse the ACS's guidelines but declined. So did the American College of Physicians. Cindy Pearson, spokesperson for the National Women's Health Network, a Washington advocacy group, supports their decisions. "Painful as it is," she says, "given the enormous need for detection of breast cancer in younger women, we do not recommend mammography screening before fifty or before menopause." Both Pearson and Love suggest that younger women use mammography only to evaluate suspicious lumps.

Even the NCI's support may be wavering. Last February it held a two-day meeting in Washington, D.C., issuing a statement noting that studies of mammography in women aged 40 to 49 "have not been conclusive." According to an agency spokesperson, the NCI is reviewing its screening guidelines for women under 50.

There is some evidence that screening mammograms don't reduce mortality rates in younger women. Researchers speculate that this is because certain breast cancers tend to be especially aggressive in premenopausal women, and early detection through mammography may not do any good. In addition, younger women tend to have dense, fibrous breasts, which may lead to many false negatives—as well as false positives. Studies have shown that mammography misses as many as half of all breast cancers in younger women.

Still, the ACS stands behind its recommendation of mammograms for women in their 40s. "There is no good research that says this is not a good thing to do," says ACS spokesperson Joanne Schellenbach. The ACS bases its mammography recommendation for younger women on its Health Insurance Plan study done in New York during the 1960s and 1970s, which showed a marginal benefit from screenings for women younger than 50. The 1992 Canadian National Breast Screening Study, however, found no evidence that women under 50 benefit from regular screening mammograms. Three other studies performed in Sweden, and one in Edinburgh, Scotland, since the HIP study do not greatly conflict with the Canadian research. (Great Britain, Canada, and Sweden, in fact, do not recommend mammography for younger women.)

All of these studies, however, have been criticized. Schellenbach points out, for example, that in the Canadian research "the mammography equipment was not state-of-the-art, there was only ▶ 56

one view taken instead of two, and the studies were not adequately designed to test the hypothesis." On the other hand, in the earlier HIP study, the women who did benefit from mammograms were closer to 50 than 40 at the start of the study. Further, most of the lumps were found in women who were older than 50.

Some insiders wonder whether the profit motive contributes to the push to enlist women younger than 50 for regular mammograms. "One factor is the natural desire to find some intervention that truly reduces the suffering and death from breast cancer," says David M. Eddy, professor of health policy and management at Duke University. "It is also undeniable, however, that some parties in this debate have a strong financial incentive to do mammography. I prefer to think this is not a very strong motivating factor."

Baby boomers, many of them now in their 40s, are exceptionally health-conscious and attuned to the idea of preventive medicine. They make a good target for a mammography campaign, which may help to explain why the TV ads paid for by General Electric, Du Pont, and Eastman Kodak—all manufacturers of mammography equipment—have featured younger women. In fact, nearly 40 percent of women younger than 50 have had at least one mammogram. And if all women in the United States aged 40 to 49 followed the American Cancer Society guidelines, the mammography industry would gross close to $1 billion per year.

Meanwhile, many younger women are tempted to get a screening mammogram despite the questions. Aside from cost, they figure that there's little downside: With the new low-dose machines, the risk of side effects from radiation exposure is minimal. "The jury is still out on this issue," says Sharon Green, executive director of Y-Me, a national breast-cancer support organization. "But there's still a segment of women in their 40s whose breast cancer *will* get picked up by mammography. Although mammography is not a perfect tool, it's the best tool we have right now." ●

The New York Times Magazine
AUGUST 15, 1993 / SECTION 6

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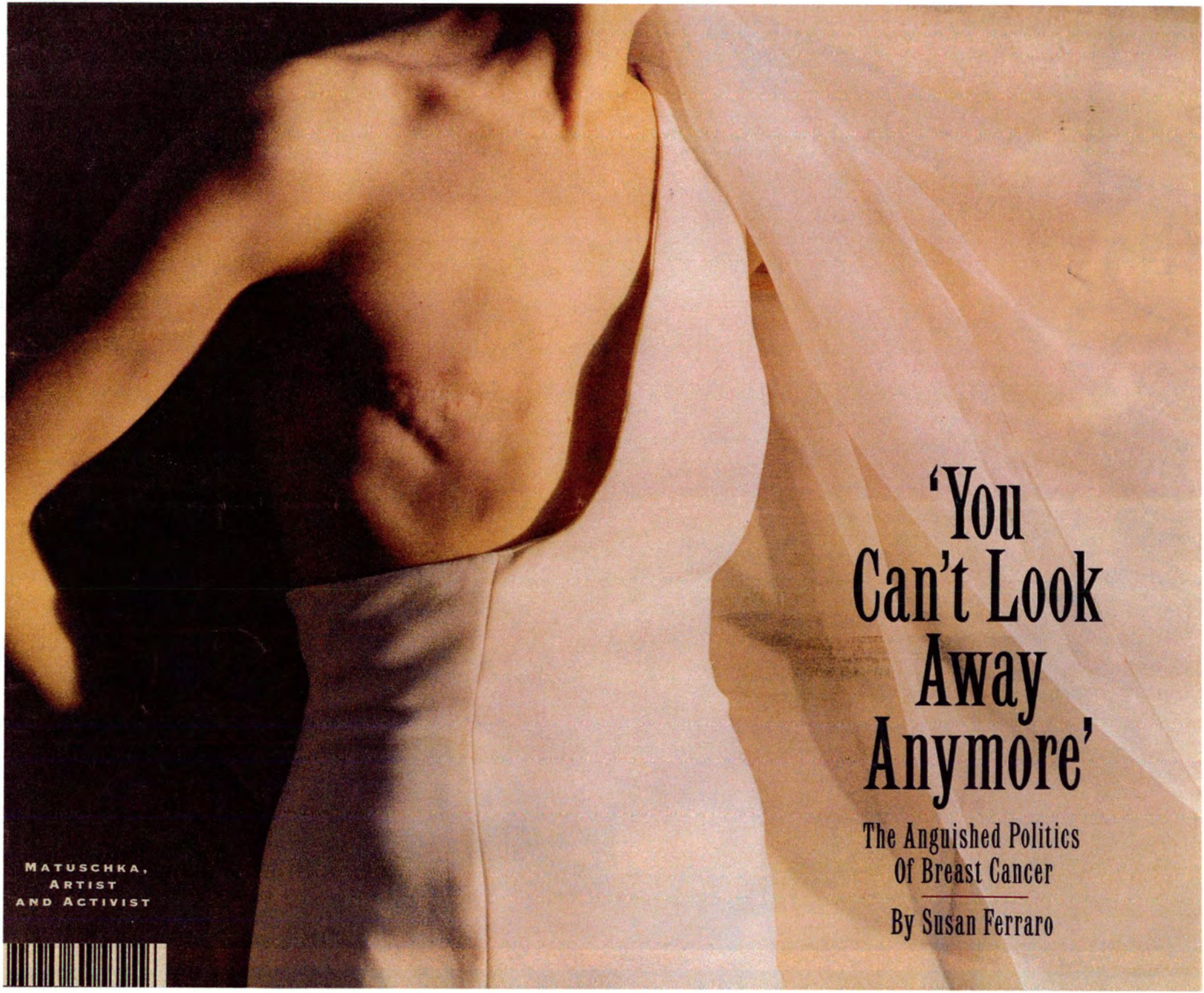


'You Can't Look Away Anymore'

The Anguished Politics Of Breast Cancer

By Susan Ferraro

The Honorable Barbara F. Vucanovich

DoD Breast Cancer Program
Luncheon Sponsored by the National Breast Cancer Coalition
February 22, 1995
11:30 - 1:30

I would like to welcome you to this informational seminar and I applaud your desire to learn about breast cancer research and the DoD breast cancer research program. It's been said "Perplexity is the beginning of knowledge". I know that is true, as the thirst for knowledge about breast cancer has left many people perplexed -- including women, scientists, and Members of Congress. For this reason, I would like to thank Colonel Irene Rich and Dr. Dennis Slamon for taking their valuable time to visit Capitol Hill to provide an overview and explanation of the DoD Breast Cancer Program. I would also like to thank the National Breast Cancer Coalition for sponsoring this important forum.

A dozen years ago, I learned I had breast cancer -- a deadly disease for which there is no cure. The terror I felt was too overwhelming for me to recount to you. It is like being a child again, afraid of the dark, only there is no parent to turn on the light and make the bogeyman disappear. Breast cancer is the bogeyman and it can get you.

Today, thanks to the federal government and private resources, scientists are feverishly working to turn on the light to exterminate the bogeyman --- breast cancer. New drugs are being discovered to attack breast cancer, flawed genes are being identified as carriers of the disease, and new detection methods such as digital mammography and ultrasound are being tested. Our successes thus far can be attributed to the fine minds of people like Colonel Rich and Dr. Slamon, and the integration of research programs like the DoD Breast Cancer Program.

The DoD Breast Cancer program is one of the most far-reaching breast cancer research programs which exists today. Extremely efficient in its structure, it has expanded research opportunities to new investigators, focused on improving access to breast cancer data, and extended innovation in research. Alone, it is but one piece of the breast cancer puzzle. But, without that pivotal part, the other pieces -- such as research programs under NIH -- do not connect. Together, the DoD Breast Cancer Program and the NIH research program can move expediently toward the goal -- finding a cure for breast cancer.

Fortunately, the federal government has responded to the need for breast cancer research and research dollars. But the growing need for breast cancer research has assisted progress in other cancer research as well. Testing for anti-cancer drug treatment has assisted ovarian cancer, gene identification is assisting research in prostate cancer, and additional progress is expected. Not to sound like one of the Musketeers but, cancer research represents the motto "all for one and one for all". Like many research programs, the DoD breast cancer research program is like a Musketeer -- courageous, resourceful, and knowledgeable. I am glad to have the DoD resources working on our team.

Benjamin Franklin said "an investment in knowledge always pays the best interest". The DoD Breast Cancer Research program fosters knowledge -- that which could pay the best interest -- a cure for breast cancer. I am highly supportive of the program and am hopeful that your attendance today is representative of your favor of the program and the goal to win the war against breast cancer.

BARBARA F. VUCANOVICH (R-NEVADA)
Member of Congress
Second District, Nevada

Congresswoman Barbara F. Vucanovich, the first woman elected to a federal office in Nevada, is serving her seventh term in the House of Representatives. Barbara has risen in stature and rank, serving on the powerful Appropriations Committee and becoming the first Nevadan to serve in a leadership position in the U.S. House of Representatives.

Elected as Secretary of the Republican Conference for the 104th Conference, this position places her among the Republican Leadership, giving Barbara an opportunity to help shape the direction of legislative policy. Barbara is also a respected member of the powerful Appropriations Committee, serving as Chairman of the Military Construction Subcommittee, Vice Chairman of the VA-HUD-Independent Agencies Subcommittee, and a member of the Interior Subcommittee.

Perhaps her toughest battle came in 1983, newly elected to serve in Congress, she was diagnosed with breast cancer. Despite undergoing surgery, Barbara never missed a vote. Today she is more active than ever in legislative matters concerning breast cancer research. She has also made preventive care and affordable mammogram a legislative priority.

Since that time, Congresswoman Vucanovich has worked with other Members to pass legislation to provide Medicare coverage for screening mammographies. Barbara Vucanovich has introduced legislation to extend this coverage on an annual basis for women who are over age 65. She has also introduced legislation to extend coverage for screening mammography under the Medicaid Program. Both bills have received bipartisan support.

During her tenure, Congresswoman Vucanovich has worked with the Food and Drug Administration regarding the safety of breast implants and the need for national mammography quality standards. She has worked closely with the American Cancer Society, the National Coalition for Breast Cancer and other health organizations to make breast cancer detection and breast cancer research a focus of the Administration.

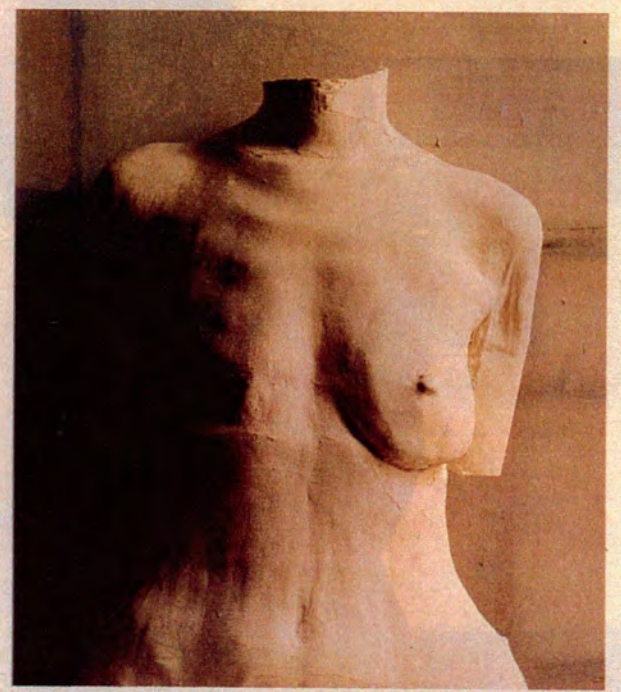
Beyond her involvement legislatively, Congresswoman Vucanovich has helped get the word out about breast cancer to communities in Nevada, as well as other states. She has hosted numerous breast cancer fairs and information forums in Nevada, provided testimony at hearings throughout the country on the importance of early detection, and is an honorary member of the Race for the Cure Committee which organizes a run/walk for Breast Cancer in Washington, D.C. Barbara, her husband, and her Congressional staff have participated in the race.

Barbara Vucanovich is committed to leading the fight against breast cancer during her time in Congress.

Strength in numbers: Members of the 1 in 9 Long Island Breast Cancer Action Coalition. Back row, from left: Louise Levine, Joan Flaumenbaum, Liz LoRusso, Cummins. Middle row, from left: Karen Miller, Francine Kritchik, Yvonne Schmidt, Barbara Balaban. Front row: Geri Barish, Susan Kaplan.

ABOVE: KAREN KUEHN/MATRIX, FOR THE NEW YORK TIMES. RIGHT: MATUSCHKA

The Anguished Politics of Breast Cancer



Forcing people to see what cancer does: "Invasive Art," a plaster cast of the artist Matuschka's torso after her right breast was removed. Her poster-size self-portraits have shocked even some of her mainstream sisters. They

Taking their cue from AIDS activists, a growing army of survivors press angrily for more money, more research—and more respect

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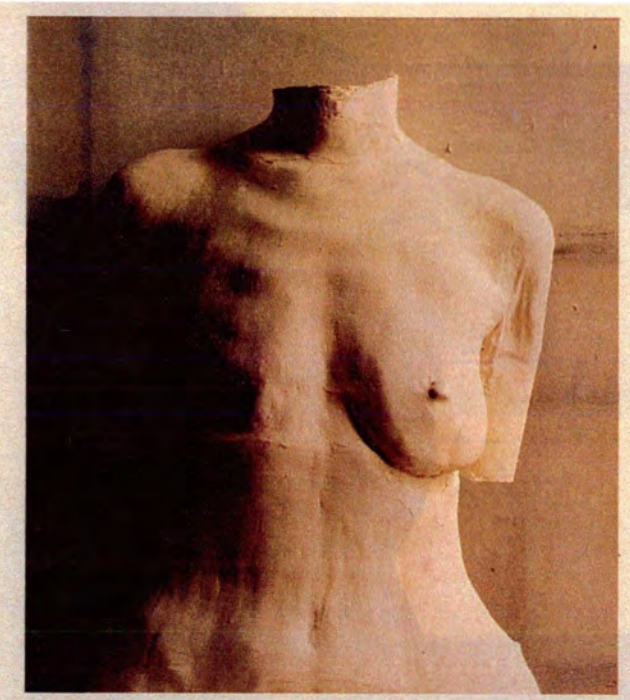


Forcing people to see what cancer does: "Invasive Art," a plaster cast of the artist Matuschka's torso after her right breast was removed. Her poster-size self-portraits have shocked even some of her mainstream sisters. They will soon be available on postcards.

Taking their cue from AIDS activists, a growing army of survivors press angrily for more money, more research— and more respect.

By Susan Ferraro

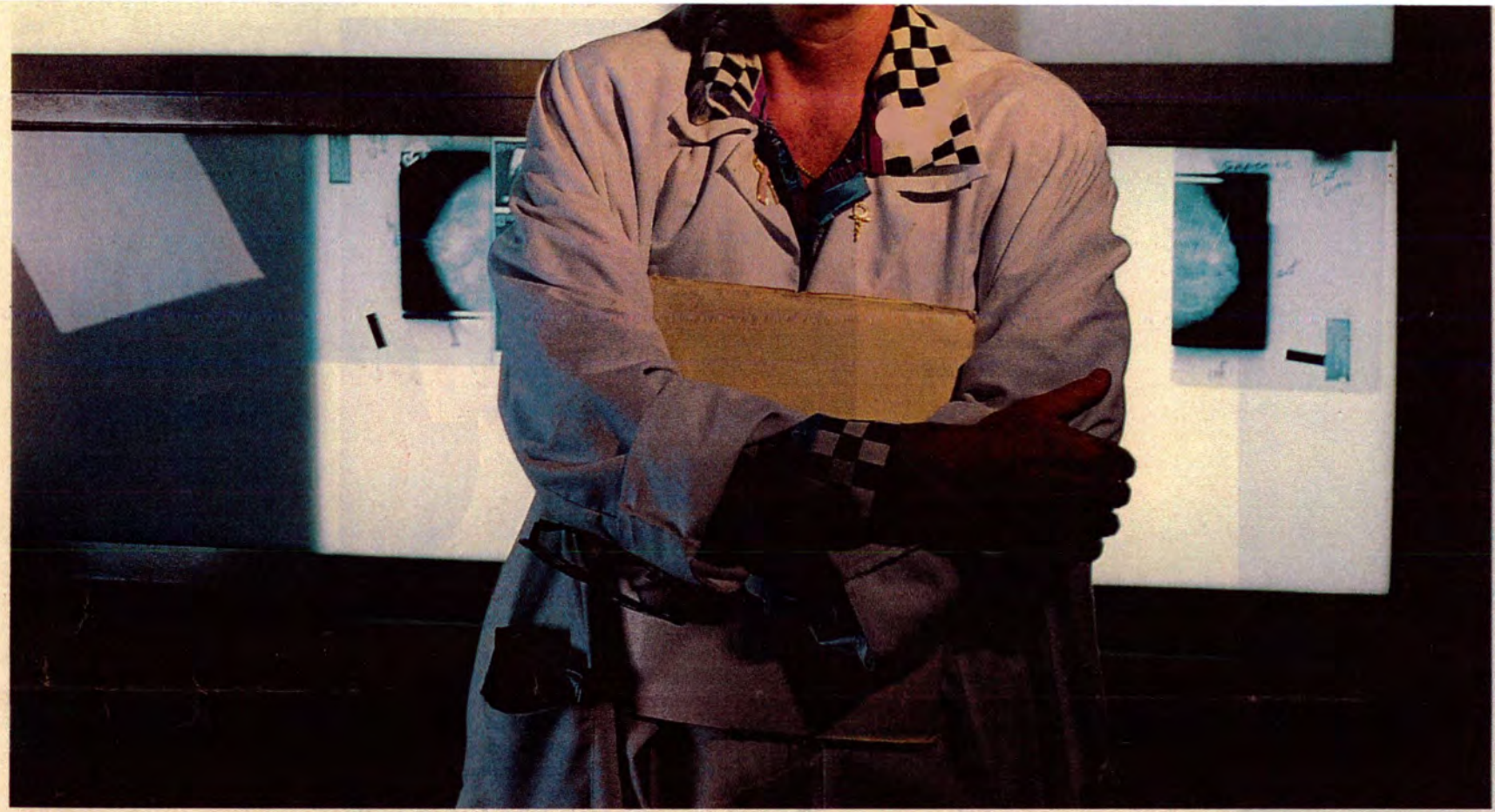
SOMETHING HAPPENED TO LIZ LORUSSO during radiation treatment for breast cancer. "I asked to be covered," she says, "and this guy, the technician, told me, 'There's no modesty in a hospital; only 80-year-old women get upset over this.' I went home and that statement ate at me all night, *just like a cancer*."

The next day, once again lying face up on the table, she looked at the technician and said: "Do you remember what you said to me yesterday about modesty? Well, *you* go get your testicles cut off, lose every hair on your body from the top of your head to the tip of your toes, then lie down on this table and have someone draw all over your crotch with a Magic Marker and we'll see how *you* like it."

LoRusso discovered the lump in her breast four years ago. She was 37. The lump turned out to be advanced third-stage cancer. The disease, which traveled to her spine and pelvis, now is "under control." She has started taking tamoxifen, a drug prescribed in an experimental cancer-prevention program — the first of its kind.

"I was never political, never," says LoRusso, a home economics teacher who is on disability leave. She lives in Huntington, L.I., in a pleasant two-story ranch, and chauffeurs her two kids after school, runs errands and

Susan Ferraro writes frequently on women's issues.



Dr. Susan M. Love, director of the U.C.L.A. Breast Center, says early detection "is not early enough."

frets about dinner and dust. "I was the peacemaker, the people pleaser. I had 16 years of Catholic school. The nuns said 'Jump.' I said, 'How high?' "

Liz LoRusso is less obedient now. She has joined 1 in 9, an advocacy group that takes its name from a commonly quoted statistic on the incidence of breast cancer. These women ask hard questions about environmental factors that may lie behind Long Island's suspected cancer clusters and high breast cancer rate. LoRusso wonders if something in the environment played a part in her disease. She thinks the "establishment" has patronized women and neglected or ignored the facts about breast cancer.

"They said it could be cured, that I had 60 percent chance of no recurrence in five years," LoRusso says. "The truth is I had 60 percent chance of being *alive* in five years." Her voice slides into the supersweet sarcasm that very polite women use when they are very angry. "Don't you just love it? Isn't it just *slightly* misleading to confuse recurrence with *survival*?"

How many angry women does it take to make a revolution? Inspired by AIDS activists in the 1980's, women with breast cancer are turning scores of support groups into a national political advocacy movement. Most of them, like LoRusso, are amateurs at activism, more comfortable speaking up for their children or their families than for themselves. The energy that drives them is anger. They say they've had it with politicians and physicians and scientists who "there, there" them with studies and statistics and treatments that suggest the disease is under control.

On the cover of a pamphlet about radiation therapy from the National Institutes of Health is a drawing of a woman receiving treatment. "She's fully clothed, she's got a blanket; she's even got a pillow." says LoRusso. "The reality is that where you once had a breast now resembles a page out of the Hagstrom road atlas. They put you on a slab, with a sheet. You're exposed .... They take Polaroid pictures and anyone can see because there's a TV camera with a monitor outside the room.

FROM LEFT, DAVID BUTOW FOR THE NEW YORK TIMES; STEPHEN SHAMES/MATRIX, FOR THE NEW YORK TIMES; MARILYN HUMPHRIES/IMPACT VISUALS.

"They stroke your hand and say, 'Don't worry, you'll be all right.' I'm angry because I'm a realist."

There are more than 180 advocacy groups, including 1 in 9, united under the National Breast Cancer Coalition, a largely voluntary organization founded in 1991. The activists are demanding more money for research, and getting it. But they want more — a big say in how that money is spent. They are impatient with research that focuses only on early detection and treatment rather than the causes of breast cancer.

"Early detection is not early enough," says Dr. Susan M. Love, director of the U.C.L.A. Breast Center and a co-founder of the coalition. The standard treatment is surgery, radiation and chemotherapy — or as Love describes it, "slash, burn and poison."

Fran Visco, president of the National Breast Cancer Coalition, and her son, David Visco Brandolph, 7. He was a year old when her breast cancer was diagnosed.

The activists may be a health movement first, but theirs is a feminist cause as well: Many believe that breast cancer has been ignored for decades because it is a woman's disease. It may be wishful thinking on their part, but some activists suggest that breast cancer is *the* feminist issue of the 1990's.

"We have to be the voice, the obnoxious voice," Love says. "We can't shut up now."

So far, this obnoxious voice has been extraordinarily successful, surprising the women almost as much as they have surprised lawmakers. In its first year, the coalition secured a $43 million increase in national funds for breast cancer research, an increase of almost 50 percent. The next year, armed with data from a seminar they financed, the women asked for, wheedled, negotiated and won a whopping $300 million more.

They did it in part by mobilizing grass-roots support. The coalition fielded a drive for 175,000 signatures, one name for each woman who would get a diagnosis of breast cancer that year. In October 1992, "Breast Cancer Awareness Month," the coalition delivered not 175,000 but 600,000 signatures to Washington.

And they enlisted the support of a key friend — Senator Tom Harkin, Democrat of Iowa. The result was an ingenious, even startling legislative maneuver that teamed them with the Department of Defense. This is not as crazy as it sounds. The Army has thousands of women in uniform, and in 1992 it budgeted $25 million for screening and diagnosis of breast cancer. When Harkin was unable to transfer funds from the defense budget to the domestic budget, he proposed that the Army's $25 million be increased to $210 million for breast cancer research.

Joanne Howes, the coalition's lobbyist, delights in

"This year 46,000 women will die of breast cancer," she says. "I will probably be among these statistics. I will leave behind my husband and partner of 18 years, a motherless child, a devastated family and too many friends. I will not get to watch my son grow up, or grow old with my husband. And the worst part is that I am not alone. This family tragedy happens every time a new diagnosis is made, and every time a woman's life is stolen by breast cancer."

There is backlash, she says, when women speak out, but she doesn't care. "I will not go silently," Kohlenberg roars. "I will go shouting into that dark night; enough is enough."

On the sidelines, Kohlenberg's close friend, Kendra McCarthy, wipes away tears. "She's dying, and she knows it," McCarthy says. Angrily jabbing a finger toward the Capitol, visible over the trees, she adds: "We've gotten in those people's faces, and we're going to stay there."

If they see themselves as combatants in a life-or-death battle, breast cancer activists make an odd sort of army. They wear buttons and hats and T-shirts emblazoned with slogans: "Draw the Line at 1 in 9," "Silent No More!" and "The Wife You Save May Be Your Own."

Yet whatever their strength in numbers, they are scared individually, vulnerable. Worried that she might seem too critical of the medical personnel on whom she continues to rely, Liz LoRusso insists that although one radiation technician was insensitive, "The other technician was wonderful, a real source of inspiration; we prayed together."

A rally in Boston sponsored by the

They are achingly aware of their casualties, their walking wounded and the odds. On the way to the rally, Susan B. Kaplan, the treasurer of 1 in 9 and a patient with recurring breast cancer, discusses the language of

Fran Visco, president of the National Breast Cancer Coalition, and her son, David Visco Brandolph, 7. He was a year old when her breast cancer was diagnosed.

breast cancer has been ignored for decades because it is a woman's disease. It may be wishful thinking on their part, but some activists suggest that breast cancer is *the* feminist issue of the 1990's.

"We have to be the voice, the obnoxious voice," Love says. "We can't shut up now."

So far, this obnoxious voice has been extraordinarily successful, surprising the women almost as much as they have surprised lawmakers. In its first year, the coalition secured a $43 million increase in national funds for breast cancer research, an increase of almost 50 percent. The next year, armed with data from a seminar they financed, the women asked for, wheedled, negotiated and won a whopping $300 million more.

They did it in part by mobilizing grass-roots support. The coalition fielded a drive for 175,000 signatures, one name for each woman who would get a diagnosis of breast cancer that year. In October 1992, "Breast Cancer Awareness Month," the coalition delivered not 175,000 but 600,000 signatures to Washington.

And they enlisted the support of a key friend — Senator Tom Harkin, Democrat of Iowa. The result was an ingenious, even startling legislative maneuver that teamed them with the Department of Defense. This is not as crazy as it sounds. The Army has thousands of women in uniform, and in 1992 it budgeted $25 million for screening and diagnosis of breast cancer. When Harkin was unable to transfer funds from the defense budget to the domestic budget, he proposed that the Army's $25 million be increased to $210 million for breast cancer research.

Joanne Howes, the coalition's lobbyist, delights in telling how, when the votes went over the required 51 to pass the measure, senators who had opposed it rushed back to change their vote: "In the 'Year of the Woman,' they didn't dare go back and tell their constituents that they had voted against this successful strategy." The final tally was 87 to 4.

AS DEMONSTRATIONS IN WASHINGTON GO, THE National Breast Cancer Coalition's rally on this blazing Sunday afternoon in May is no big deal. The week before, more than 300,000 gay and lesbian Americans, many of them AIDS activists, had jammed the Washington Mall. Today only 700 or so demonstrators cluster on a patch of grass near the Reflecting Pool. There are no celebrities, no politicians looking for camera angles.

Yet the rhetoric, when it comes, is an unapologetic, confident roar of political rage. Especially riveting is Sherry Kohlenberg of Virginia. The mother of a 4-year-old boy, Kohlenberg, 37, is a small figure in black — pale but fierce. Her straw hat wobbles on her head because chemotherapy has made her hair fall out.

More? and The Wife You Save May Be Your Own.

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They are achingly aware of their casualties, their walking wounded and the odds. On the way to the rally, Susan B. Kaplan, the treasurer of 1 in 9 and a patient with recurring breast cancer, discusses the language of mortality.

"I'd rather have chronic breast cancer than be Stage 4 terminal," she says, her matter-of-fact tone almost reassuring. "You have to believe that if you have a recurrence you'll get through it. People die of asthma too, but it's chronic. Chronic means it goes on."

A rally in Boston sponsored by the Massachusetts Breast Cancer Coalition, October 1992. Congress has so far listened to the raised voices of breast cancer activists, to the tune of a $300 million increase for research.

EVEN SIGMUND FREUD COULD FIGURE out what these women want: Straight answers about a complicated disease that threatens their lives, and a coherent public policy based on those answers.

"When I was diagnosed I was stunned," says Frances Visco of Philadelphia, a lawyer and president of the coalition. Her son was a year old in 1987 when she learned she had breast cancer. "I had no family history, and I felt that meant that I was O.K., that I didn't have to worry about it. When I started reading of this disease, I thought I was seeing misprints. If this is true, why didn't I know about it?"

One reason, Love asserts, is that "the medical profession and the media have sort of colluded to make it sound like if you do *(Continued on page 58)*

CANCER

(Continued from page 27)

your breast self-exam and you get your mammogram, your cancer will be found early and you'll be cured and life will be groovy."

Mammograms are the best diagnostic tool available, but by the time a cancer shows up on a mammogram, she says, it could have been there eight years, for much of that time having access to blood vessels that can ferry stray cancer cells to vital organs.

As recited by advocates at every opportunity, the statistics that don't get much publicity are startling. Right now, they say, 2.6 million women in the United States have breast cancer — 1.6 million who know it, 1 million who don't.

Scientists know that smoking contributes to lung cancer and they know something about the gene that goes haywire in colon cancer, for example, but no one has any idea what causes breast cancer, the leading cause of death in women ages 35 to 52. The mortality rate for black women is 10 percent higher than for white women, although they get breast cancer less frequently. The overall mortality rate for breast cancer — 27 deaths per 100,000 women — has remained the same for 50 years, and its incidence has increased steadily in what the coalition insists is an "epidemic," though cancer specialists do not agree.

Even the identification of high-risk factors — having a close relative with the disease, early menstruation, late menopause, giving birth at a later age is key. Diet, exposure to electric power lines ("If you want to believe that," he says) and early exposure to DDT in the food chain may also be factors, but Kessler carefully distances himself from these suggestions.

tics are needlessly alarming to women, and statistics are always slippery.

Larry G. Kessler, for example, chief of the applied-research branch at the National Cancer Institute, confirms that mammograms spot cancers that have been in the breast for "some time," but he says the assumption that they have been there eight years is not necessarily true, since some cancers grow faster than others.

It is true, he says, that overall mortality rates have remained the same, but have recently increased in women over 50 and decreased in women under 50. "Different cohorts, or groups of women born at different times, bring different risks of death with them," Kessler says. He suspects that a trend in giving birth at a later age is key. Diet, exposure to electric power lines ("If you want to believe that," he says) and early exposure to DDT in the food chain may also be factors, but Kessler carefully distances himself from these suggestions.

statistic is the oft-repeated assertion that "one in nine" women will get breast cancer. Most people take that to mean one in nine women *anywhere* — at the grocery store, at a P.T.A. meeting. But the figure is based on a life expectancy of 85 years: if all women lived to be 85, one in nine could expect to have a diagnosis of breast cancer at some time.

"There's only one reason to use those numbers," says Elin Bank Greenberg, chairman of the Susan G. Komen Breast Cancer Foundation, headquartered in Dallas, a national breast cancer organization that is not part of the coalition, "and that is to frighten women." The reality, she says, is that "among women aged 50, one in 50 will get the disease; the rate increases with age, and the true risks are being female and getting older."

The dispute over how to read the numbers is distracting, in part because statistics change and are open to endless interpretation. "This is not a competitive

Clara Piha undergoes mammography at Memorial Sloan-Kettering Cancer Center in New York. By the time cancer shows up on a mammogram, stray cancer cells could have already been ferried to vital organs.

To win "a place at the table" they are kicking off another signature-gathering campaign, this time for 2.6 million names. (While steadfastly pursuing its own agenda, the 10-year-old Komen Foundation, which runs dozens of "Race for the Cure" events each year, is pitching in to help collect the signatures.) And coalition members are training themselves as lobbyists, educators and publicists.

IN A SENSE, THE breast cancer movement began when prominent women — coincidentally all of them figures in Republican Party politics — went public with the disease: Shirley Temple Black in 1972, and even more influentially, the First Lady, Betty Ford, in 1974, followed by Happy Rockefeller, wife of the Vice President. The television reporter Betty Rollin also pushed the issue into the public consciousness with "First, You Cry," a best-selling book about her breast cancer in 1976. Until these women spoke out, breast cancer was barely mentionable, a disease that women saw as shameful and humiliating. It eroded a woman's sexual confidence and identity, and was an essential fact that her best friends often did not know.

In the late 1970's, support and information groups began to form tight, nurturing bonds between women who might otherwise never meet: rich and poor, white and black, gentile and Jewish, lesbians and straight women, Republicans and Democrats. Terrified of death and disfigurement, the women sought others who had been through the tough treatments and the

breast cancer activists are (so far) less confrontational than some AIDS activists about their right to more medical research. But they also know that being nice often gets you nowhere, and that outrageousness works well in the political arena. Betsy Lambert, a Manhattan lawyer and board member of the national coalition, says "you've got to admire" the people who make an uproar. Lambert says she has had moments when she wants to be outrageous, perhaps even pelt indifferent bureaucrats with breast prostheses.

Activists like Matuschka — a tall, striking artist in New York — set out to shock. As a member of a small group called WHAM (Women's Health Action and Mobilization), Matuschka makes art of her mastectomy with poster-size, one-breasted self-portraits that force people to see what cancer does. Though some of her mainstream sisters are discomforted by the graphic images, they admire her determination. As she says, "You can't look away anymore."

More commonly, activists have taken the orderly route of lobbying, collecting signatures, working the system, confident that they can prevail by sheer numbers.

Certainly, one thing the movement has going for it is timing — noisy 1960's activists who are in their 40's and 50's and baby boomers who were nursed on 60's activism are increasingly at risk for breast cancer. They understand the power of group politics. "I wasn't a *famous* activist, but I protested the war in the 60's," says Visco, the breast cancer coalition's president. "I spoke out for women's rights in the '70's."

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Even the identification of high-risk factors — having a close relative with the disease, early menstruation, late menopause, giving birth late in life or not at all — is not the news it seems to be. Depending on which expert is quoting what study, 70 to 85 percent of women who get breast cancer have no known risk factors. Only 5 percent of all breast cancers are inherited.

"This isn't 'high risk,'" says Barbara Balaban, who is director of the Breast Cancer Hot Line and Support Program at the Adelphi University School of Social Work on Long Island and a member of the coalition's working board. "This is *a* risk. What are the ones we don't know about?"

Many scientists and even some breast cancer organizations say that such statis-

Clara Piha undergoes mammography at Memorial Sloan-Kettering Cancer Center in New York. By the time cancer shows up on a mammogram, stray cancer cells could have already been ferried to vital organs.

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Kessler allows that the coalition is "close enough" when it estimates that 1.6 million women have the disease (his own figure is 1.5 million), but he questions whether there are 1 million undiagnosed cases of breast cancer. If all women who have not been screened with mammography were to be tested, he estimates that there would be "about 162,000" more cases found. The one million unknown cases cited by the coalition, "may be based on estimates of tumor growth times and other approaches," he says. "I cannot verify this number, and I believe you should be very careful about using it."

One especially arguable women aged 50, one in 50 will get the disease; the rate increases with age, and the true risks are being female and getting older."

The dispute over how to read the numbers is distracting, in part because statistics change and are open to endless interpretation. "This is not a competitive issue," Greenberg says. "It is unacceptable that in the decade of the 90's, an estimated 1.5 million women will be diagnosed, and 500,000 will die."

The coalition wants the Federal Government to spend $659 million for breast-cancer research in 1994. They want access to screening for all women, including the uninsured. In addition, the coalition wants a "comprehensive national strategy" on the issue, coordinated from the White House. "The problem now is that there are isolated pockets of people looking at breast cancer, and no one is talking to anyone else," says Fran Visco. "These turf battles are fought, and we lose."

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During the 1980's, AIDS activists showed how anger could be put to good use, and breast cancer groups started to stretch their agenda beyond coping to the idea of curing. Like homosexuals announcing their sexual orientation, women frequently describe the first time they tell friends about their cancer as "coming out."

Since 1980, some 194,000 people have died of AIDS and 450,000 have died of breast cancer. The difference, as the television commentator and breast cancer survivor Linda Ellerbee points out, is that AIDS is always fatal and "some of us survive."

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In 1990, the publication of "Dr. Susan Love's Breast Book," a comprehensive and widely respected work co-written with Karen Lindsey, brought Love into the public eye. She is an engagingly direct and human surgeon who can laugh about her daughter's Barbie doll or fuss over not having had time to change from a blue suit rumpled on the red-eye from Los Angeles. Speaking before 500 coalition members in Washington, she drew a roar of laughter with a comment on the breast-squeezing mammogram apparatus that so many women hate: "It was indeed invented by a man, and I think there's a good

PHOTOGRAPH BY SARA KRULWICH/THE NEW YORK TIMES

tool we could invent for them with a little of our money."

In December 1990, Love met with Susan Hester, a Washington fund-raiser and director of the Mary-Helen Mautner Project for Lesbians With Cancer, to discuss formation of a national lobby. They called Amy S. Langer, executive director of the National Alliance of Breast Cancer Organizations, and the three set up the coalition in skeletal form. Within a year there were 150 member groups, then 180, and it's still growing.

One of the most active groups in the coalition is 1 in 9. The Northeast in general has a high rate of breast cancer, and Long Island's rate is especially high. According to one set of statistics, in the 1980's there were 94.7 cases of breast cancer for every 100,000 women; in Nassau County on Long Island, the rate was 110.6 cases. For years there has been talk of scattered cancer clusters on Long Island — not just for breast cancer but all forms of the disease.

What would eventually become 1 in 9 began in 1987, after Francine Kritchek, a petite blond grandmother and teacher, had a mastectomy; Marie Quinn, a friend from work, admitted what she had told no one before: she, too, had breast cancer. The next year, Kritchek and Quinn sent a letter about the disease to everyone in their school.

But what really got them going was a state study of Long Island's breast cancer that found a relationship between high breast cancer incidence and high levels of our model," Kritchek says. "They showed that if the populace became very concerned, then the politicians would respond."

Under pressure from 1 in 9, the Breast Cancer Support Program and Senator Alfonse M. D'Amato, the Federal Centers for Disease Control held a public hearing on the need for another study. Members of 1 in 9 and others testified about suspected environmental risk factors, like auto emissions, polluted water, toxic wastes, pesticides and electromagnetic fields.

"Six months later they said the earlier study was sufficient!" Kritchek snorts. Rejecting the conclusions of the C.D.C report, 1 in 9 held a news conference with Senator D'Amato in January on "discrepancies," "archaic thinking" and "patronizing implications" in the report.

The group also pledged to organize a study of its own in November, led by two breast cancer researchers, Susan Love and Dr. Devra Lee Davis of the National Academy of Sciences. Other groups, meanwhile, are distributing and tabulating questionnaires to identify possible clusters in Huntington, West Islip and Long Beach.

ACTIVISTS FOR the National Breast Cancer Coalition say they want a cure. But is money — even unlimited Federal funding — the answer? The millions of dollars allocated and used for AIDS research has not yet produced promising results. The Komen Foundation researcher working on prostate cancer may find a benefit that has a splash effect on breast cancer."

Amy Langer, now vice president of the coalition, says there is a dearth of basic information on the breast. "Because so little is known about what's normal, about why cancer cells react the way they do and how we can control them," she says, "research is vital." For example, Langer says, technicians have had what she diplomatically calls "limited" success in working with human breast cancer cells in vitro. And there are issues like drug resistance on a cellular level: "Why does cancer stop responding to some chemotherapy, and why does chemotherapy knock out some cells but not all of them?" Langer asks.

Coalition leaders like Love think that money earmarked for breast cancer research can answer some of these questions, as well as throw light on how breast cancer starts.

"Basically, all cancer is genetic," says Love. "It's not all hereditary, but it's all genetic. What that means is, it's all a gene that screws up." Carcinogens, she says, interfere with normal genes. "What are these carcinogens in breast cancer? We don't have a clue. Could they be hormones? Sure. Could they be a virus? Sure." It could be pesticides, food additives or "a million" other things.

At the National Cancer Institute, Kessler is sympathetic to the movement's goals, but doubtful of its success. In his expert opinion, he says, "clinically, it's going to be impossible to detect" the first liest mutations, and "maybe we can reverse the progress and development of breast cancer." The involvement of the Department of Defense in financing breast cancer research is fortunate, she believes, because it will spark productive competition between Federal agencies seeking a cure. Researchers go where the money is.

As the coalition's clout has grown, the powerful scientific and legislative communities that perhaps inevitably resist change have begun to hedge their objections to the advocates' assertions and demands. It's hard if not impossible to criticize mothers and sisters who are fighting cancer. Still, one challenge, generally voiced off the record, is that the coalition's determination to get more money for breast cancer will mean less money for other diseases. Critics squirm at the thought of "politicizing" medical research.

The coalition members describe this as backlash. "We don't want a bigger piece of the pie," they repeat again and again. "We want a bigger pie." They say research has always been political, because there has never been enough money for research. "Someone has been making the decision to fund 'X' at the expense of 'Y.' For too long those decisions have been made at the expense of women's lives," says Visco. "We've come along and we've said enough, stop; you have to start spending more of that money on breast cancer."

According to a story that Lesley Stahl of CBS News told at a charity lunch, Congress first saw breast cancare to cover mammograms. It was a complicated issue, and the bill had to go through an all-male subcommittee. There were few breast cancer activists then, but a female lobbyist approached a congressman and asked him to introduce the necessary language in a larger health care bill.

His response personified Capitol Hill politics: "I did the women's thing last year," he said. "The guys will think I'm soft on women."

Her response was sexual politics: "Fear not. Just tell them you're a breast man."

Ultimately, the necessary language was inserted in the bill; the legislation passed, only to be lost when the entire catastrophic-health-care bill was repealed. But when George Bush became President, he needed the Congressional women's votes to pass his budget, and they again asked for mammogram coverage. The President agreed, but said he'd have to swap it for something else, Stahl says: funds for a children's program called Wee Tots.

In the last two years, since its collective consciousness was raised by Anita Hill's testimony at the Clarence Thomas hearings, Congress has learned to pay more respect to women's issues, including breast cancer. In part, this is because more and more lawmakers have personal experience with the disease. Senator Harkin, who championed the $210 million in defense money for breast cancer, lost two sisters to the disease. Representative Nita Lowey, Democrat of New York, lost her mother and two aunts; she has sent a letter to President

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But what really got them going was a state study of Long Island's breast cancer that found a relationship between high breast cancer incidence and high levels of household income. The study deemed environmental factors negligible, and said no further studies were warranted.

Women all over Long Island were outraged by the state's conclusions, among them Kritchek and Quinn, who later died of her cancer. They contacted Balaban at Adelphi, put a small ad in the local paper and sent a mailing to hundreds of people announcing a meeting. "Fifty-seven angry, frustrated women showed up," Kritchek says. Soon 1 in 9 was making local headlines, most notably with a protest by 300 women, some in wheelchairs, in front of the courthouse in Nassau County.

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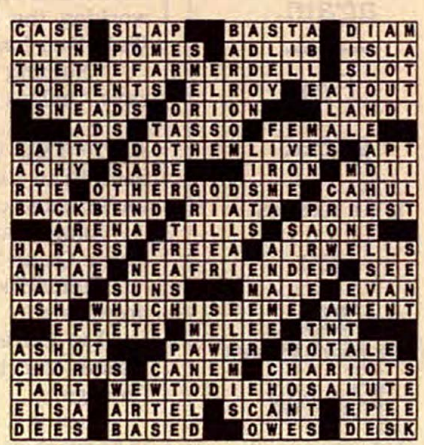
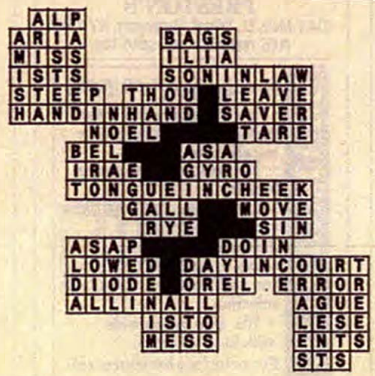
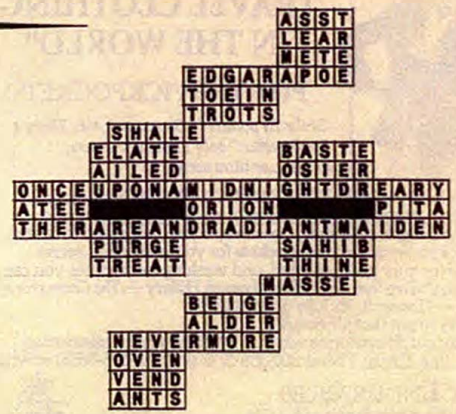
ANSWERS TO PUZZLES OF AUGUST 8, 1993







bara Vucanovich, Republican of Nevada, and Marilyn Lloyd, Democrat of Tennessee, are themselves survivors and have made breast cancer issues part of their legislative proposals.

In the Senate, Patrick J. Leahy, Democrat of Vermont, arranged for the coalition to show its formal display, "The Faces of Breast Cancer," in the rotunda of the Russell Senate Office Building for a week. Although Senator Orrin G. Hatch, Republican of Utah, was one of the four who voted against Harkin's $210 million Defense Department maneuver, he has since sponsored a bill requiring public health programs to provide clients with information about cervical and breast cancer.

"So what?" say some activists, implying that Hatch's response was trivial. But Lowey is encouraged. "You build support where you can get it," she says.

DURING THE WASHINGTON WORKSHOPS in May, in a session called "Identifying Opportunities for Influence," Sheila L. Swanson of the Bay Area Breast Cancer Network in San Jose, Calif., tells the audience: "We have to make it clear: We may have had mastectomies, but we did not have a lobotomy." Her listeners cheer, and the next day several hundred of them buoyantly hurl themselves into the world of big-time lobbyists. Their inexperience sometimes can work for them; after all, these are voters first, lobbyists second. But other times inexperience leads to emotionally bruising confrontations.

In the office of Senator Daniel Patrick Moynihan, a dozen women believe they have an appointment with the Senator at 12:30 P.M. He is not there; an aide will speak with them. The meeting room is unavailable. Grumbling a little, the novice lobbyists — some of them using canes because their cancer has spread to the spine, others pasty-faced from chemotherapy — follow her to a dimly lighted basement lunch room full of workers grabbing a quick bite or smoke.

Scattered wrappers and bits of food litter the tables. Several women sweep the table tops clear before sitting. They push close to hear; the din from the vending and change-making machines is constant.

Yet they stick to their script: "As you sit here, every 12 minutes a woman dies." And: "What we're doing now probably will not save our lives. We're doing it for our daughters, and our sisters." They end, as instructed by workshop leaders, on a positive note, thanking the aide for the Senator's past support.

Afterward, in the hallway, Kritchek is furious. "Never in all my years have I been treated like this," she says. "It was insensitive, it was offensive." Brian

Network in San Jose, Calif., tells the audience: "We have to make it clear: We may have had mastectomies, but we did not have a lobotomy." Her listeners cheer, and the next day several hundred of them buoyantly hurl themselves into the world of big-time lobbyists. Their inexperience sometimes can work for them; after all, these are voters first, lobbyists second. But other times inexperience leads to emotionally bruising confrontations.

In the office of Senator Daniel Patrick Moynihan, a dozen women believe they have an appointment with the Senator at 12:30 P.M. He is not there; an aide will speak with them. The meeting room is unavailable. Grumbling a little, the novice lobbyists — some of them using canes because their cancer has spread to the spine, others pasty-faced from chemotherapy — follow her to a dimly lighted basement lunch room full of workers grabbing a quick bite or smoke.

Scattered wrappers and bits of food litter the tables. Several women sweep the table tops clear before sitting. They push close to hear; the din from the vending and change-making machines is constant.

Yet they stick to their script: "As you sit here, every 12 minutes a woman dies." And: "What we're doing now probably will not save our lives. We're doing it for our daughters, and our sisters." They end, as instructed by workshop leaders, on a positive note, thanking the aide for the Senator's past support.

Afterward, in the hallway, Kritchek is furious. "Never in all my years have I been treated like this," she says. "It was insensitive, it was offensive." Brian Connolly, Moynihan's press secretary, later describes the way the meeting went as "unfortunate," but says the group had erred by not letting him know that journalists would be coming.

A few days later, at home in Hicksville, L.I., Kritchek is upbeat: giving interviews, making dinner, working the telephone and planning 1 in 9's next Walk-Run fund-raising event.

"Nothing will ever happen to breast cancer," she says, "unless it is politicized."

AS OF THIS WRITING, THE COALITION'S President, Fran Visco, has been named to President Clinton's cancer panel.

Long Island's 1 in 9 gave Fran Kritchek the first Marie Quinn Memorial Award.

Matuschka is making one-breasted self-portrait postcards.

Liz LoRusso is considering starting an experimental vaccination program for breast cancer in Chicago.

Sherry Kohlenberg, the woman who promised not to go silent into the dark night, met with Bill and Hillary Rodham Clinton in June. She died on July 14. ■

file

The National Breast Cancer Coalition Fund
a grassroots advocacy effort

P.O. Box 66373
Washington, DC 20035
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CONGRESSIONAL FORUM SERIES

A Briefing on the Department of Defense Breast Cancer Research Program

February 22, 1995

The National Breast Cancer Coalition
a grassroots advocacy effort

P.O. Box 66373
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FACTS: DOD Breast Cancer Research Program

How the Program Came About:

- Began in 1991, the National Breast Cancer Coalition's (NBCC) first priority was to increase the amount of money appropriated by the Federal Government for breast cancer research.
- As a result of NBCC's work with Congress, in 1992, $210 million was appropriated to the Department of Defense (DOD) for peer reviewed breast cancer research.
- In 1993, $25 million was appropriated for the DOD breast cancer research program and critically, Congress included language stating that the program should continue.
- Again, in 1994, NBCC fought hard to continue the program. With strong bi-partisan support, $150 million was appropriated for the DOD peer reviewed breast cancer research program.

How the Program Works:

- The Army entered into an agreement with the Institute of Medicine (IOM) to develop a strategy for allocating the funds.
- The IOM put together a committee of the highest caliber, including Harold Varmus, M.D., Mary-Claire King, Ph.D., Kay Dickersin, Ph.D.,and other renowned scientists, who recommended a programmatic strategy and process to the Army.
- A Request for Proposals was broadly disseminated and over 3,000 proposals were received in response.
- Put through a rigorous peer review process, over 1,200 proposals were deemed of sufficient merit to warrant funding.
- These proposals were ranked by score and presented to a panel made up of distinguished scientists and consumers who then reviewed the proposals and ranked them for overall programmatic relevance. The funds appropriated were sufficient to fund 460 of the 1,200 proposals deemed worthy.

-MORE-

The DOD Breast Cancer Research Program has Accomplished:

- Healthy competition among researchers that motivates innovative ideas and new approaches to research in areas of environmental and genetic research among many others.

- New scientists have been attracted to the field of breast cancer research: both scientists starting out in research, as well as established scientists who bring years of research experience and knowledge, have joined the fight against this disease.

- The creation of new model of a "lean and mean" research program where 91% of the dollars go directly to research that can be applied to all areas of bio-medical science in the DOD and throughout the scientific community.

- The continuation of the program will be a cost effective use of the structure that the Army has created. The Army stands ready to proceed with continued and expanded research.

- Greater attention to women's health care needs within the military. Women in the military and military dependents have been overlooked for too long.

- By the year 2,000, 20% of all members of the military will be women. Currently, a large number of military personnel and their dependents are treated in military medical facilities. Finding the cause of, and cure for breast cancer will save billions of health care dollars.

- New, highly productive relationships have been forged between the Army and the academic, research, and consumer communities.

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BACKGROUNDER ON DOD

This is a background paper to be used by NBCC members who are lobbying for the DOD program. Under no circumstances should this document be shown or given to any member of Congress or staff or to anyone other than the NBCC members who are lobbying.

How the program came about:

In Fiscal Year 1993, $210 million of the Department of Defense research and development budget was allocated for a peer reviewed breast cancer research program administered by the Department of the Army. This program came about because of the work of the National Breast Cancer Coalition. One of the first priorities of the Coalition was to increase the amount of money appropriated by the federal government for breast cancer research. Prior to the Coalition's existence the federal government spent $90 million on breast cancer research. During the first year of the Coalition's lobbying for increased funds, that number went up by $42 million, to $132 million. The Coalition next held its own research hearings in February 1992 to develop a plan and to determine how much the government should be spending on breast cancer research. As a result of those hearings, the Coalition came up with a plan by which the federal government could and should spend an additional $300 million for breast cancer research - for at total of $432 million. We were successful in getting the money - $196 million of it in the domestic budget at the National Cancer Institute and $210 million in the Department of Defense - for the first time getting new dollars for this disease, rather than reallocating dollars from other diseases to breast cancer.

How the program worked:

The Army recognized that it lacked expertise in this area and so it entered into an agreement with the Institute of Medicine (IOM). The IOM was charged with coming up with a strategy by which the money should be spent. The IOM put together a committee of the highest caliber, including Harold Varmus, Mary Claire King, Kay Dickersin, and other renowned scientists, who recommended a programmatic strategy and a process to the Army. The Army then implemented that strategy. A Request for Proposals was broadly disseminated and approximately 2700 proposals were received in response. Those proposals were then put through a rigorous peer review process, where the proposals were evaluated for scientific merit. Approximately 1200 proposals were deemed of sufficient merit to warrant funding.

These proposals were ranked by score and then were presented to a panel made up of distinguished scientists and consumers who then reviewed the proposals and ranked them for overall programmatic relevance. The funds appropriated were sufficient to fund 460 of the 1200 proposals deemed worthy.

What the program accomplished:

The $210 million in the Department of Defense budget for breast cancer has been hugely successful. The money has gone to fund innovative science of the highest caliber, and has attracted new scientists to the field of breast cancer research: both scientists starting out in research as well as established scientists who have moved to breast cancer. It has galvanized the scientific community.

What happened next:

This year (1994) we fought to get the program refunded (for the 1995 budget). We were successful - the DOD budget includes $150 million for the peer reviewed breast cancer program.

The Problem:

With the election of a new Congress, the new DOD committees are looking at the defense budget and have been quoted as saying they want to rescind - take away - all non-defense items in the budget. They have specifically identified the breast cancer research program as a non defense related item that they want to rescind. We simply cannot let that happen.

Why should the DOD program continue (Talking Points):

The existing research structure at NIH had become stale and offers little opportunity for innovative ideas, new faces or new approaches. While it is extremely important to continue and indeed increase the funding mechanism at NIH, at the same time, funding through the DOD has: created a "kick start" to new areas; an avenue for established researchers to move into breast cancer research and for new scientists to begin their careers focusing on this area; and, also has created an atmosphere of healthy competition that is influencing the way NIH does business. This is important because the statistics on breast cancer are so devastating, the incidence is rising and the mortality rate has not changed. We treat breast cancer the same way we have for decades. We do not know how to prevent breast cancer or how to cure it. The length of time since a woman's diagnosis does not really matter - a woman once diagnosed forever lives with the threat of incurable recurrence.

We are at a point in breast cancer research where increased funding and a new approach can make a significant difference in the search for answers. Recent discoveries in the area of genetics have changed our understanding of the disease and now form a basis upon which to build new discoveries. These discoveries also must be taken from the laboratory to the bedside - we must translate the exciting discoveries of how cells operate into actual treatments.

The women in the military and the women who are military dependents - both active duty and retirees - have been overlooked for too long. This program will be of immense benefit to them.

This program funds peer reviewed research - not "pork". Congress is not making the determination of which proposals, or whose research warrants funding; it has acknowledged that the decision is appropriately made by scientists. This program is the best use of research funds - it goes to the best science that can have practical application for citizens. It goes to research that has been determined by scientists to be of the highest scientific merit and that will most efficiently and rapidly meet the programmatic goals of the DOD program.

SUPPLEMENTAL TALKING POINTS

The National Action Plan on Breast Cancer - a collaboration of scientists, government, industry and consumers - lists as a priority continuation of the Department of Defense peer reviewed breast cancer research program.

The DOD Appropriation Committee report last year stated that "The Department should continue this important program in future budget requests."

The National Breast Cancer Coalition
a grassroots advocacy effort

P.O. Box 66373
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TO: State Coordinators, NBCC Board Members, NBCC Members

FROM: Fran Visco

RE: DOD Alert

Once again Congress is attempting to take away money from the DOD breast cancer program. As you know, this year, against all odds, we were again successful: we won another $150 million for breast cancer research in the Department of Defense budget. This will enable us to continue the DOD program - an innovative, highly successful program, that has won acceptance by scientists, the Department of the Army and breast cancer consumers.

The staff of the Defense appropriations subcommittees of the 104th Congress - that will start on January 4, 1995, has targeted "non-defense related" items in the Department of Defense budget. It has specifically identified the breast cancer research program as an area that can be eliminated. WE CANNOT LET THIS HAPPEN. We must go all out on this one.

We are asking that you send out alerts to your network: asking people to fax, to call, to write, to send postcards, to visit in the home districts, to get support for keeping the $150 million for the DOD breast cancer program.

This will be more difficult than usual - we are not certain of phone numbers, or fax numbers, since Congress itself is in a state of flux - Members are moving offices and shifting staff. But, we also hear that the move to take away our money may come as early as January - so we can't wait. We have to make as much noise as possible beginning NOW.

We are sending you two packets: One, for your use, includes background information, talking points, an alert, sample press release, and some other general information that you will need. The other packet is to hand to the Member of Congress or his or her staff representative. Your packet also includes everything that is in the Member's packet.

For several state coordinators, we know the number of congressional districts in which you have strong representation. We are sending those state coordinators packets for each of those districts also.

If you have questions about the packets, please call Sharon Ford Watkins at the Washington office, 202/296-7477 - x102. THANKS!!

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WHAT TO DO

The decision on whether to rescind the breast cancer money will be made by the DOD appropriations subcommittees, and the chairs of these subcommittees have a great deal of power. We need you to get the message to those subcommittee members who are in your state and most importantly to the chairs, regardless of whether the chair is in your state. The more people the subcommittees hear from, the more likely we are to be successful. We also need you to get your Senators and Representative to support keeping the program and to put pressure on the subcommittees to keep the program.

(1) Activate your alert network.

(2) It is ok to send the same message in different ways so your network can - fax, telephone, send letters and use our prewritten postcards. The message must continue to get to Congress, so don't stop after the first week. It is ok if over time the same person sends more than one message.

(3) Put the pressure on both in Washington and locally, in your districts. The new Congress goes into session January 4, 1995. We will schedule a lobby day in Washington, but recognize that most of you will be unable to attend. To focus on Washington, use the fax, phone and mail.

(4) Locally, personal visits are the most effective. Schedule visits at the district offices of your Senators and Representative. If possible take others with you. Ask to meet with the staff members familiar with Defense and Health issues. We have provided packets for you to leave with them. Ask for a commitment that the Senator or Representative will actively oppose rescission of the DOD Breast Cancer Program, and will both send a letter and in person request of the committee chair that the program be protected. Don't leave the meeting without establishing a contact person for your future inquiries and concerns on this issue.

(5) Establish a schedule to continue visits on this issue and have your network continue to make calls asking congressional staff for updates. You should personally call the contact person on a weekly basis during the first weeks of the session.

(6) Remember that new members of Congress may not know very much about breast cancer. This can also be the case for returning members. A major part of our advocacy is to educate members of Congress about breast cancer. Use the breast cancer fact sheet in your packets and leave a fact sheet with the staff members or member of Congress with whom you meet.

(7) Use the press. Included in your packet is a press release. Also, look at the DOD list and see which institutions in your state received DOD funding. Ask the local press to do a story on that research. Make certain you point out to the senator or representative or their staff that the DOD program brought money to their state/district.

(8) Use the report form in your packet to keep the NBCC office informed about your activities.

THE WHITE HOUSE

WASHINGTON

FEB 16 1995

February 10, 1995

The Honorable William J. Perry
Secretary of Defense
The Pentagon
Washington, D.C. 20301

Dear Secretary Perry:

The President was very disturbed to read in today's Washington Post that the Department may not be spending the funds provided by Congress for breast cancer and AIDS research. He asked that I make clear his position with respect to this issue.

The President believes that research to combat these deadly diseases is vitally important to all Americans, and it is of special significance to him. Every year, we are losing 46,000 women to breast cancer, and some 183,000 women are diagnosed with the disease. Last year, 40,000 Americans died of AIDS. The President believes that we cannot afford to allow these tragic losses to continue. And that is why breast cancer and AIDS research is a high priority for this Administration.

As you continue to carry out this important program, please keep the President advised of your progress.

Sincerely,

Leon E. Panetta
Chief of Staff

April, 1994

STATEMENT OF CERTAIN MEMBERS OF THE SCIENTIFIC COMMUNITY IN SUPPORT OF CONTINUATION OF THE DOD BREAST CANCER PROGRAM

In 1993 approximately 183,000 American women were newly diagnosed with breast cancer; 46,000 died of the disease. Today there are 2.6 million American women living with this disease: 1.6 million who have been diagnosed and an estimated one million who do not yet know they have breast cancer. For all American women, the incidence of breast cancer has been steadily rising since the 1940's; mortality rates remain constant. We do not know how to prevent breast cancer or how to cure it. The statistics are staggering; the cost to this nation in lost lives, lost productivity, medical costs and families impacted is horrifying.

In a time of scarce resources, it is clear to the public and the scientific community that we can no longer rely solely on traditional sources of funding for biomedical research. While our research resources are diminishing, the incidence of breast cancer is rising. The 1993 DOD Breast Cancer Program provides an excellent and innovative method to address this conflict.

Recognizing that the breast cancer epidemic cannot be addressed solely by one agency, President Clinton in the Fall of 1993 asked the Secretary of Health and Human Services to sponsor a summit to bring together consumers, scientists, representatives of private industry, the media and government, to begin the design of a national action plan to address all aspects of breast cancer. The continuation of the DOD breast cancer program was one of the recommendations to come out of the Secretary's breast cancer conference.

As scientists and consumers who are members of the USAMRDC Breast Cancer Integration Panel we urge that this program receive ongoing funding. We have seen first hand the benefits of the program. Rather than redirect dollars away from other biomedical research, the DOD project provides a vehicle to bring new dollars to breast cancer. In addition, this program has been broadly defined such that the research performed will be of benefit not just for breast cancer, but for all cancers and other diseases.

The 1993 DOD program saw an influx of 2,700 proposals for funding, many of which were submitted by researchers for whom the traditional research structure has not provided opportunities. A basic tenet of the program is to bring new ideas, individuals and institutions to this area of research. The program provides an entry for women and minorities into the research structure and is designed to encourage individuals with less experience in the scientific community. Innovative mechanisms in the DOD program also provide vitally important training opportunities for new scientists and for those who wish to redirect the focus of their careers. A category of IDEA grant has attracted innovative research proposals and the special sabbatical grant mechanism opens doors for established researchers to work in new breast cancer areas.

The overall structure of the DOD program has streamlined the entire funding process while retaining traditional quality assurance mechanisms. Moreover, we have seen a structure begin to develop for the support of translational research, a vital yet underfunded area of science.

Science exists today in an atmosphere of uncertainty. Too often when appropriations must be trimmed, Congress has looked to science to sacrifice its already limited resources. This has resulted in a scientific community that lacks needed dollars to fund research and new researchers, and in aging infrastructures unable to compete in the international scientific arena, let alone to support innovative, ongoing research. For too long the scientific community has remained silent and permitted this to happen. The members of the scientific community who join in this statement recognize that we cannot afford to lose the new opportunity the DOD program for breast cancer research provides. We have a chance to make up for some of the losses we have incurred over the past decade.

We urge that Congress again fund this necessary biomedical research program.

Anna D. Barker, Ph.D.
President and Chief Executive Officer
International BioClinical Inc.

Robert W. Day, M.D., M.P.H., Ph.D.
Director, Fred Hutchinson Cancer Research Center

Kay Dickersin, Ph.D.
Department of Epidemiology and
Preventive Medicine
The University of Maryland at Baltimore
Co-Chair, Research Task Force
The National Breast Cancer Coalition

Laurie Lee Fajardo, M.D.
Department of Radiology
University of Virginia

Harold P. Freeman, M.D.
Director, Department of Surgery
College of Physicians & Surgeons of Columbia University
Harlem Hospital Center

Emil Frei III, M.D.
Professor of Medicine and Physician in Chief,
Emeritus
Dana-Farber Cancer Institute

Jean E. Johnson, Ph.D., F.A.A.N.
Professor and Clinical Chief for Oncology Nursing
University of Rochester School of Nursing

Peter A. Jones, Ph.D., D.Sc.
Director, USC/Norris Comprehensive Cancer Center
1441 Eastlake Avenue
Los Angeles, CA 90033

Mary B. Mahowald, Ph.D.
Assistant Director, Center for Clinical Medical Ethics
The University of Chicago

Harold L. Moses, M.D.
Director, Vanderbilt Cancer Center
Vanderbilt University Medical Center

Marsha D. McNeese, M.D.
Associate Professor of Radiotherapy
Department of Radiation Therapy
The M.D. Anderson Cancer Center

James E. Potchen, M.D., J.D.
Chairman, Department of Radiology
Michigan State University

Catherine Reznikoff, Ph.D.
Professor of Human Oncology
University of Wisconsin Medical School

Jean L. Richardson, Dr.P.H.
Department of Preventive Medicine
University of Southern California School of Medicine

Helene S. Smith, Ph.D.
Director, Geraldine Brush Cancer Research Institute

Elizabeth A. Hart, R.N.
Chairman of the Board
The Susan G. Komen Breast Cancer Foundation

Frances M. Visco, Esq.
President, National Breast Cancer Coalition

BREAST CANCER

Army Doles Out Its First $210 Million

The Army is used to traversing mountains. But even experienced troops might balk at climbing this one: 2700 grant proposals averaging 60 pages apiece, copied 20 times—3 million sheets of paper, enough to fill a half mile of shelving in a warehouse at Fort Detrick, Maryland. Those are the dimensions of what may be the largest single peer-reviewing effort the U.S. Army has tackled—a breast cancer research program, created with a $210-million windfall from Congress in 1992. "The logistics have been a challenge," concedes Colonel Irene Rich, the program's director since March. But last week, with a touch of pride, the Army finished its year-long slog over a mountain of paper and announced 433 winning proposals.

Scientists, even those who have said they would prefer to see the money channeled through the National Cancer Institute (NCI), are welcoming the results, which are heavily weighted toward investigator-initiated projects in basic cancer biology. Frederick Becker, a member of NCI's National Cancer Advisory Board and research chief of the M. D. Anderson Cancer Research Center in Houston, says he's "buoyed" by the award list. "These are really good projects. ... and the mix of people seems to be remarkable—some very well-known names but a lot of people I would have to guess are young or middle-level scientists," Becker says.

Becker's opinion is significant, given that some scientists had been concerned about how the interests of scientists and breast cancer activists would be balanced after the National Breast Cancer Coalition (NBCC), an advocacy group composed mostly of breast cancer survivors, got Congress to put the funds in the defense budget. Others worried that the money would go for mammography equipment rather than for basic science. But those fears were eased when the Army reacted favorably to an Institute of Medicine (IOM) study that recommended spending the bulk of the money on peer-reviewed biomedical research (*Science*, 21 May 93, p. 1068).

The Army then solicited proposals, and last winter, a contractor scrambled to organize 615 reviewers into 41 study sections to gauge the scientific merits of 2680 submissions. A 19-member integration panel organized by the Army narrowed the list to 408 winners. At least 25 more proposals on a wait list will be funded with the $24.2 million Congress gave the program for 1994.

The final breakdown matches the IOM plan quite closely. Investigator-initiated research grants make up 78% of the awards, with one third in genetics and the remainder spread among molecular biology, clinical, psychosocial, and etiological projects. Topics range from sequencing breast cancer genes to the role of radiation in causing breast cancer to a study of the cancer's effects on Puerto Rican women. Also following the IOM closely, another 12% will pay for training grants to support graduate students, postdocs, and midcareer scientists who want to switch to breast cancer studies. The remainder will fund "infrastructure" projects such as tissue banks and information networks. (About 7% of the total was spent on administration.)

Breast cancer activists also seem to have received much of what they wanted, according to University of Maryland epidemiologist Kay Dickersin, who is an NBCC board member, a breast cancer survivor, and a member of the integration panel. Dickersin says the Army has been "excellent to work with," and that the awards meet the expectations of NBCC. But, she says, next time her group would encourage more psychosocial and epidemiologic proposals. In addition, it wants activists to be included in the study sections, not just the final integration panel.

And it seems there will be a next time. Two weeks ago, Congress allocated $115 million in the Army's 1995 budget to begin the proposal process anew. That came as a surprise to researchers such as Becker, who thought the Army program was one time only. But "we didn't," says Dickersin. "The importance is, this is a whole new pie."

–Jocelyn Kaiser

Following orders. Distribution matches plan drafted by the Institute of Medicine.

SPACE EXPLORATION

Visionaries Swap Pointers on Star Flight

Most space scientists spend a lot of their time worrying about how to get their instruments into orbit around Earth. But a small band of nearly 100 scientists, engineers, and visionaries who gathered at New York University (NYU) in late August had a much bigger problem on their minds: how to fly a robotic probe to a nearby star. They discussed dozens of strategies—many, they argued, only just beyond current technology—and some daunting hurdles the venture would face.

High hopes. Riding a particle beam to the stars.

Perhaps the biggest technical problem is a kind of Catch-22: A craft small enough and fast enough to satisfy the propulsion experts may be too small to send a detectable signal back home. And in interstellar flight, even small and fast does not mean cheap. But this was not a defeatist gathering. "There has been incremental advance in every aspect of this field," said Edward Belbruno, the University of Minnesota research associate who organized the meeting with support from NYU, the United Nations, and the Planetary Society. Added Lawrence Livermore National Laboratory physicist Jordan Kare, "We are within striking distance of proposing a precursor mission" that would fly beyond the solar system, if not to a nearby star.

To have any chance at all with funding agencies, participants agreed, a mission to the stars must last no longer than 50 years, so that prospective funders and participants would have some chance of seeing the results. Reaching a star such as Tau Ceti (11.4 light-years away) or Barnard's Star (6 light-years) on that schedule would mean traveling at up to a third of the speed of light. And that implies a probe weighing no more than a few kilograms.

Thanks to advances in microelectronics and sensor technology, building an instrument package that small may be a feasible goal, said Kare, who helped develop sensors for the lightweight Clementine mission to the moon and is now working on a Pluto mission called the Pluto Fast Flyby. And the propulsion system that accelerates the craft need not add much weight—because most or

*Practical Robotic Interstellar Flight: Are We Ready? 29 August–1 September.

ILLUSTRATION BY ED BELBRUNO AND DAEDRON MELVIN / THE GEOMETRY CENTER

United States Senate

WASHINGTON, DC 20510

September 19, 1994

The Honorable Ted Stevens
Ranking Member, Subcommittee on Defense
Committee on Appropriations
United States Senate
Washington, D.C. 20510

Dear Mr. Stevens:

In 1992, we took an important step in the battle against breast cancer. With your help, Congress appropriated $210 million to the Department of Defense for breast cancer research. This year, we ask you to renew your commitment to this effort for the sake of the 2.6 million women living with breast cancer today as well as all of the women who will face it tomorrow.

The Army Breast Cancer Research Program has been a resounding success -- increasing current research efforts as well as inspiring new efforts on the part of some of the nation's best and most experienced researchers. The Army received over 3,000 proposals in response to a solicitation for breast cancer research projects. A successful peer review process funded over 400 of these innovative proposals with the original $210 million appropriated by Congress. There were several hundred additional meritorious proposals that were left unfunded.

Clearly, there is tremendous interest in this program and many other avenues of research to pursue if we continue to fund this effort. If funding for this program is not continued in a consistent and committed way, the incentive to plan and pursue new research will be gone, the momentum will be lost, and we will lose the ground we have gained in battling this disease.

We know that the Subcommittee was faced with many program requests and a limited number of dollars this year, and we appreciate your support for the Army Breast Cancer Research Program. We want to work with you to build on that support and increase the funding for this program to the House-approved level of $150 million.

The eradication of breast cancer has become a national priority, but we still have a long way to go in this battle. The Army Breast Cancer Research Program is a valuable resource in our effort to defeat this terrible disease.

Thank you for your continued leadership on this issue and your consideration of our request.

Sincerely,

Patrick Leahy

Dianne Feinstein

Arlen Specter

Tom Harkin

Barbara Mikulski

Alfonse D'Amato

Patty Murray

Wendell Ford

Jim Sasser

Frank Lautenberg

Joseph R. Biden, Jr.

Barbara Boxer

Paul Sarbanes

Dennis DeConcini

Paul Simon

Howard Metzenbaum

Harris Wofford

Bill Bradley

Carol Moseley Braun

George Mitchell

Thomas Daschle

Christopher Dodd

James Jeffords

Edward Kennedy

Daniel Patrick Moynihan

Daniel Akaka

Frank Murkowski

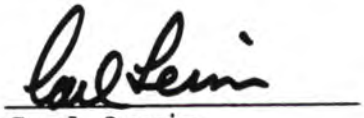
Claiborne Pell

David Pryor

Charles Robb


John Warner


Max Baucus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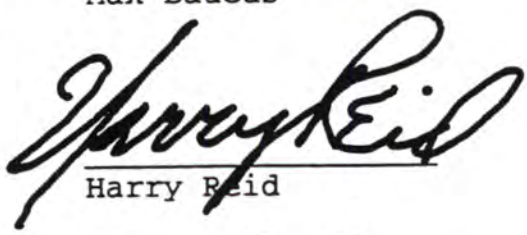
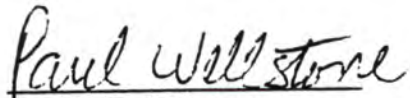
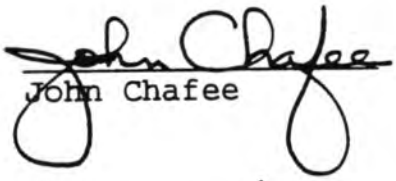
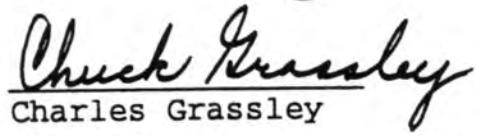

Harry Reid


Paul Wellstone


John Breaux


John Chafee

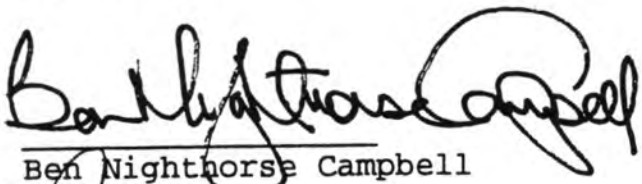

Russ Feingold


Charles Grassley

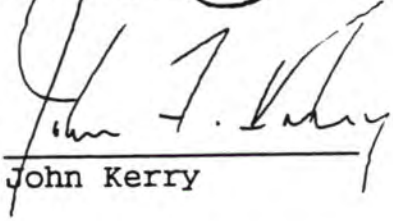

William Cohen

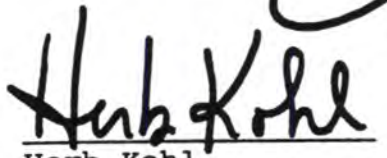

Bob Graham


Jay Rockefeller


Ben Nighthorse Campbell


Donald Riegle


John Kerry


Herb Kohl

J. Bennett Johnston

Howell Heflin

Richard Bryan

Kent Conrad

Harlan Mathews

William V. Roth, Jr.

Congress of the United States

House of Representatives

Washington, DC 20515

January 23, 1995

The Honorable Floyd Spence
Chairman
National Security Committee
U.S. House of Representatives
Washington, D.C. 20515

Dear Chairman Spence:

As members of the Congressional Caucus for Women's Issues, we are writing to you to express our serious concern about recent proposals to eliminate all Defense Department programs that do not strictly support national defense.

We are particularly concerned that these proposals would eliminate funding for breast cancer research currently being conducted by the Department of Defense. As of October 1994, the Department had awarded 433 grants and contracts for research in the areas of infrastructure enhancement, training and recruitment, and investigator-initiated research. Additional grants and contracts will be awarded with funds appropriated for FY 95.

We recently received some of the first good news we have had in the fight against breast cancer. Mortality rates for breast cancer victims decreased by more than 4% between 1989 and 1992. While we all agree that this is excellent news, the good news is not equally spread. Rates of mortality due to breast cancer among African-American women did not decline over this period. Moreover, the decrease in mortality does nothing to alter the fact that 1 in 8 women in America are stricken by breast cancer. We must keep up the momentum we have helped to create, so that we can one day cross the threshold and find a cure for this disease. We owe it to American women and their families to continue the fight against breast cancer.

The Defense Department has been an important force in the cause. It has access to certain technologies that could prove crucial to detection of breast cancer -- and currently, early detection is the only means for reducing the likelihood of death resulting from breast cancer. The FY 94 Defense Appropriations conference report reads: "The committee is aware of high quality, non-ionizing ultrasound imaging research that can portray in real time and in high resolution, the condition of internal human

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tissue. It is also aware of a new development that can produce high quality, full breast x-ray imaging digitally. These imaging technologies can be powerful tools for initial detection and for improving treatment efficacy, as well as for lowering costs related to breast cancer. The Defense Department, therefore, plays an essential role in the fight against breast cancer.

Elimination of funding for breast cancer research under the Department of Defense would set back the nation's progress in breast cancer research. We cannot break faith with the millions of American women and their families who are relying on the vital research that the Federal government supports. We encourage you not to forget that important fact, and urge you to maintain funding for the breast cancer research conducted by the Department of Defense.

Sincerely,

Nita M. Lowey
Co-Chair

Connie Morella
Co-Chair

Eddie Bernice Johnson

Patsy T. Mink

Marcy Kaptur

Pat Danner

Corrine Brown

Cynthia McKinney

Jane Harman

Nydia Velázquez

Lynn Woolsey

Barbara-Rose Collins

Zoe Lofgren

Karen L. Thurman

Nancy L. Johnson

Marge Roukema

Lynn N. Rivers

Lucille Roybal-Allard

Eleanor H Norton

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Breast Cancer Advocacy

FORGING AHEAD IN 1995

The National Breast Cancer Coalition is a grassroots advocacy organization dedicated to the eradication of the breast cancer epidemic through action and advocacy. Since its inception in 1991, the Coalition's membership has grown to more than 300 organizations, representing several million patients, professionals, women, their families, and friends, and tens of thousands of individual members.

The accomplishments of the NBCC have fundamentally changed our nation's deadly indifference to breast cancer. NBCC has:

- built a grassroots network of advocates across the country, with members in every state.
- successfully fought for a five fold increase in federal funds for breast cancer research.
- targeted President Clinton with 2.6 million signatures which resulted in his commitment to create a National Action Plan to end breast cancer.
- established working relationships with the nation's lawmakers and prestigious medical and research institutions.

Hotel

The Washington Marriott
Located at 22nd and M Streets in Washington's West End. Only fifteen minutes from Washington National Airport and Union Station. Three block walk to either Foggy Bottom or Dupont Circle Metro Station. Adjacent to Georgetown's neighborhood, boutiques, and restaurants.

$149 per night + tax, single or double occupancy triple/quad $20 additional per person + tax. Call 202-872-1500 or 800-344-4445. Be sure to request the group rate for the National Breast Cancer Coalition.

Special Thanks

To Our Sponsors
Bristol-Myers Squibb Oncology Division
Revlon
The Streisand Foundation
The Blue Ridge Foundation
Coloplast, Corp: featuring Amoena & Discrene brands

This conference is a project of the National Breast Cancer Coalition Fund.

Overview of Events

Sunday April 30

12:00 NOON-5:00 PM: Registration.
12:30-2:00 PM: Lobby Day Briefing.
3:00-4:30 PM: Organizational Membership Meeting.
5:30-7:00 PM: Reception for Conference attendees.

Monday May 1

7:00 AM: Registration.
8:00 AM-4:45 PM: Third Annual Advocacy Training Conference.

Tuesday May 2

10:00-10:45 AM: Lobby Day Briefing.
10:45 AM-5:00 PM: Annual NBCC Membership Lobby Day on Capitol Hill.

Registration

Open registration begins at noon on Sunday at the Washington Marriott. This is an opportunity for you to pick up name tags, workshop assignments and conference materials the day before. Registration is required for attendance at reception.

Reception

The National Breast Cancer Coalition invites conference registrants to a reception at the Washington Marriott. This is a unique opportunity to meet NBCC Board, Staff and Conference Speakers, and a time to network with breast cancer activists from across the country. The reception is included in the conference fee.

Organizational Membership Meeting

Organizations that are current members of NBCC are entitled to send a representative to the Annual Membership Meeting. The meeting will update members on our activities and provide an opportunity to ask questions and offer suggestions.

Annual NBCC Membership Lobby Day and Briefings

This year NBCC will hold two lobby briefings to ensure that all your questions and concerns are addressed before we send you off to lobby your representatives on Capitol Hill. Packets of informtaion will be handed out at the briefings. If you are planning to attend Lobby Day, attendance at one of these briefings is critical. Lobby Day briefings will be held on Sunday at the Washington Marriott and again on Tuesday morning before lobbying begins on Capitol Hill. A bus will be available to take participants from the Marriott to Capitol Hill on Tuesday morning.

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Volume 1,
Numbers 1 & 2
Winter/Spring 1994

Call to Action

THE QUARTERLY NEWSLETTER OF THE NATIONAL BREAST CANCER COALITION

One thousand breast cancer advocates marched from the National Museum of Women in the Arts to the Ellipse on October 18, 1993 — demanding a national strategy to end the breast cancer epidemic.

Dear Activists,

I am extremely pleased to introduce the premiere issue of our quarterly newsletter, *Call to Action*. There is so much to report, we decided to make this a double issue. This newsletter is about the grassroots organizations that make up the Coalition and the actions we are taking in our ongoing fight to eradicate the breast cancer epidemic. We recognize that an effective grassroots network requires informed and educated advocates with whom we regularly communicate. We are committed to making this network as forceful and productive as needed to achieve our goals. This newsletter is an important step in that direction.

Our efforts have escalated from the first signature drive in October 1991, through research hearings in February 1992 and our $300 Million More! campaign to the culmination of Campaign '93 – our drive to collect 2.6 million signatures on a petition to the President. You, our members, sponsors, supporters and friends, surpassed that goal in less than six month's time, and on October 18, 1993, two hundred Coalition members and friends stood in the East Room of the White House and presented President Clinton with 2.8 million signatures.

Our 1993 efforts did not rest with the petition drive. Our work helped increase the domestic appropriations for breast cancer research by another $100 million. We also worked to increase funding for the Department of Defense breast cancer program, and we received an additional $25 million for that project, which has attracted close to 3,000 proposals and is moving forward rapidly. The $210 million appropriated last year plus this year's $25 million will be allocated to exciting and innovative research projects over the next several months.

The landmark accomplishments of last year are only a beginning. Our strength lies in you – our membership and grassroots network. We will continue to wage the war and speak out as long as women continue to live in fear of breast cancer.

Fran Visco
President

The National Breast Cancer Coalition
A grassroots advocacy effort

Barbara Balaban
Adelphi Breast Cancer Support Program

Kerrie Wilson
American Cancer Society

Judith Tuller
American Jewish Congress

Kay Dickersin, PhD
Arm-in-Arm

Nancy Evans
Breast Cancer Action

Bunny Zintak
Breast Cancer Advocacy Network

Arlyne Draper
California Breast Cancer Organization

Betsy Lambert, Esq.
CAN ACT

Jane Reese-Coulbourne
DC Area Chapter, NBCC

Judy Hirshfield-Bartek, RN
Faulkner Breast Centre

Eleanor Smeal
Fund for the Feminist Majority

Frances M. Visco, Esq.
Linda Creed Breast Cancer Foundation

Ann Maguire
Massachusetts Breast Cancer Coalition

Amy Langer
National Alliance of Breast Cancer Organizations

Cindy Pearson
National Women's Health Network

Roslyn Grace
That's What Friends Are For

Susan Kaplan
1-in-9/Long Island Breast Cancer Action Coalition

Sue McCain
SHARE

Susan Hester
The Mary-Helen Mautner Project for Lesbians with Cancer

Susan Love, MD
UCLA Medical Center

Kendra McCarthy
Virginia Breast Cancer Foundation

Trish Robertson
Women's Community Cancer Project

Sharon Green
Y-ME National Organization for Breast Cancer Information and Support

Organizational affiliations for identification purposes only

The National Breast Cancer Coalition
1707 L Street, NW, Suite 1060
Washington, D.C. 20036
(202) 296-7477
(202) 265-6854 fax

♻

THE National Breast Cancer Coalition

NBCC

NBCC gave me so much hope, and I transformed from a breast cancer "victim" to a breast cancer Survivor/Activist! I can't tell you what this has meant to me and my family.

The National Breast Cancer Coalition

CHALLENGING INDIFFERENCE, CHANGING THE RULES.

In 1991, a small group of women confronted a growing national tragedy and decided they had to change the country's mindset about breast cancer. They refused to accept the chronic underfunding of breast cancer research. And they refused to be defeated by the conspiracy of silence and indifference surrounding a disease that claims the lives of 46,000 American women each year — a disease that has become the leading killer of women aged 35-44 and the major cause of cancer death for African American women.

With vision and determination, these women formed the National Breast Cancer Coalition, an organization with a unique focus: ***action*** and ***advocacy*** to end breast cancer.

The Coalition has built a grassroots network of advocates across the country, with members in every state. More than 300 organizations and tens of thousands of individuals bring their power and voice to our network. This remarkable grassroots coalition has forever altered the way that scientists, health care providers, the government, and private industry deal with breast cancer. It has empowered all those whose lives are touched by this disease.

The members of NBCC are survivors, as well as the children and parents, spouses, partners, and friends of those who survive...and those who have not. Our supporters and member organizations encompass the universe of groups that care about this issue, including physicians, nurses, scientists, legislators, and others.

The National Breast Cancer Coalition has fundamentally changed our nation's deadly indifference to breast cancer. NBCC's Campaign '93 targeted President Clinton with 2.6 million petition signatures and resulted in the President's full commitment to a National Action Plan to fight breast cancer. NBCC was a chief architect of this unprecedented plan, which outlines concrete action steps in the areas of health care, national policy, and research.

The Coalition also advances change through a National Action Network, nationwide conferences for advocates, and extensive media education. Our input is now sought by the nation's lawmakers and prestigious medical and research institutions.

Perhaps the most important change we've brought about is acceptance of the idea that breast cancer survivors ***must*** have a say when policies are formed and research funding decisions are made.

"The National Breast Cancer Coalition [has] transformed breast cancer from a closely guarded secret — an issue once considered unfit for polite conversation — and brought the issue to the front pages of our newspapers, to the front steps of American households, and to the frontburner of the national agenda."

Donna Shalala
Secretary of Health and Human Services

Benchmarks For Change

The National Breast Cancer Coalition has three major goals, and we've already made significant achievements in all three areas:

1. Increase research into the cause, optimal treatments, and cure for breast cancer.

   The Coalition was chiefly responsible for boosting federal funding for breast cancer from $80 million in 1990 to over $400 million in 1993 to $465 million in 1995.

2. Improve access for all women to high quality breast cancer screening, diagnosis, and treatment.

   With the specifics of a national health plan at stake, the Coalition has gained the attention and respect of the President of the United States and other key policy makers. Our growing National Action Network and nationwide advocate training program will help ensure that universal access to breast cancer related services and treatment remains a top government priority.

3. Increase the influence that breast cancer survivors have over research, clinical trials, and national policy.

   NBCC was the driving force behind a precedent-setting National Summit on breast cancer, convened by the U.S. Secretary of Health and Human Services in December, 1993. This summit resulted in the world's first comprehensive National Action Plan on Breast Cancer.

   The Coalition's President was named Co-Chair of the National Action Plan implementation process. She was also appointed to the three-member President's Cancer Panel, which monitors the national cancer program.

   Members of the Coalition are also invited to testify before Congress and to participate on panels such as the one that oversees the $210 million Breast Cancer Research Program of the Department of the Army.

These Successes Are Just The Beginning

ONCE YOU EARN A SEAT AT THE TABLE YOU CAN NOT WALK AWAY!

Finally, women with deep personal knowledge about breast cancer have been invited into the policy and budgetary discussions that control our daughters' destinies.

Is this the time to lessen our involvement?

Finally, funding for research that may unlock the secrets of breast cancer has reached an appropriate level for one year. But life-saving answers are not found in one year.

Is this the time to relax and turn our attention elsewhere?

And still, far too many women die simply because they do not have access to quality medical screenings and treatment. Others with breast cancer cannot get employment or purchase health insurance because they suffer the stigma of their disease.

Can we let up on our pressure?

The answer to all these questions is a resounding NO! Now, more than ever, The National Breast Cancer Coalition can make a difference ...and so can you.

The Challenge Ahead

A COMPREHENSIVE NATIONAL STRATEGY IS ESSENTIAL

NBCC has mobilized the power of the breast cancer community, and now decision-makers are paying attention. Due to our work, President Clinton and Secretary of Health and Human Services Donna Shalala are fully committed to a national strategy to end breast cancer. The Action Plan exists, but now we must ensure that it is implemented, turning our early victories into long-term results.

Specifically, we must:

- Through education, turn consumers into effective advocates in the political and scientific arenas.
- Fight to continue adequate funding for research. It will take years of sustained research to understand and conquer breast cancer.
- Monitor the use of hard-won research dollars to ensure that scientists look for ways to cure breast cancer and seek innovative new treatment options.
- Ensure that breast cancer is adequately addressed in national health care reform.
- Extend and strengthen our grassroots advocacy network.

For those individuals or organizations interested in making a substantial gift to the Coalition, we have a tax-exempt education fund. For more information please call the NBCC office.

Join NBCC

ADD YOUR VOICE!

Now that we have the attention of decision-makers, we can make a difference. But we need you. Every additional Coalition supporter increases our clout in the halls of Congress and in the world of medical research. Every additional dollar enables us to train advocates, mobilize the National Action Network, bring grassroots lobbyists to Washington, and more. Your support helps bring us closer to understanding and ending the horror of breast cancer.

Yes! I want to stand up to the ignorance and indifference about breast cancer! Here is my contribution of:

__$20 __$25 __$35* __$50 __$100
__$500 __$1,000 __ Other $_____

*a gift of this amount or more entitles you to receive our quarterly newsletter, "Call to Action"

Please charge my gift to my: __Visa __MasterCard

Account # Exp. Date

Signature

My gift is in honor/memory of:

__Yes! I want to join the National Action Network and be active in NBCC's work. Please contact me.

Name

Address

City/State/Zip

Telephone (h) (w) (fax)

Please make checks payable to and mail to: The National Breast Cancer Coalition, P.O.Box 66373, Washington, D.C. 20035 (202) 296-7477

In order to keep NBCC free to lobby aggressively on your behalf, your contribution is not tax deductible.

NBCC Has Touched the Conscience of America

The President

"...[breast cancer] is not only tearing the heart out of so many families, but also has left us again with no excuse for why we would spend so much money picking up the pieces of broken lives when we could spend a little bit of money trying to save them."
President Clinton at a White House ceremony with the NBCC

Congress

"As a former Secretary of the Navy and member of the Senate Armed Services Committee, I know what it takes to wage a successful campaign. You must have capable leadership, good people and resources, and a winning strategy. The National Breast Cancer Coalition has brought these qualities to the war on breast cancer with great success. We all owe them a debt of great thanks."
John Warner, U.S. Senate (R-Virginia)

The Scientific Community

"...listening to you and your colleagues [has] made me realize personally even more strongly how much more effective we all (health care providers, scientists and breast cancer survivors) can be in eradicating this disease if we work together."
Michael Reiss, M.D., Medical Director, Yale Comprehensive Breast Care Center

The Media

"...the growing political clout of a movement dedicated to preventing, treating and curing a disease that now affects one woman in nine."
Amy Goldstein, The Washington Post

Breast Cancer in the USA

LET'S FACE FACTS

- Breast cancer is the most common form of cancer in women.
  - Every 3 minutes, another woman is diagnosed.
  - Every 11 minutes, another woman dies.
- Breast cancer is the leading cause of cancer death for African American women.
- Breast cancer is the leading cause of cancer death for all women aged 35–54.
- There is no certain cure for breast cancer. Despite growing use of mammography and overall advances in medical technology, the death rate has not changed over the last 20 years — approximately half of all breast cancer patients will die from their disease.
- We have no idea what causes breast cancer and every woman is at risk.
  - 75% of new cases are diagnosed in women with *no family history* of breast cancer.
  - Although the disease is most common in women over 50, younger women, even those in their twenties, also are diagnosed with and die of breast cancer.
- In 1990, the dollar value of medical care for the nation's breast cancer patients was estimated at over $6 billion. Federal funding for breast cancer research equals only 6.7% of that cost.

Sources available upon request.

The National Breast Cancer Coalition
1707 L Street, NW, Suite 1060
Washington, D.C. 20036
(202) 296-7477/(202) 265-6854 fax

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Volume 1
Number 4
Winter 1995

Call to Action

THE QUARTERLY NEWSLETTER OF THE NATIONAL BREAST CANCER COALITION

Paula Zahn, Susan Love and Fran Visco flank three breast cancer survivors who were recognized at our NYC gala dinner on November 14, 1994 for their volunteer efforts on behalf of the Coalition. They are (left to right) State Senator Olga Mendez, Andrea McClure and Carol Vance Wall.
Article and more photos on page 4.

Dear Activists,

On behalf of the Board of Directors of NBCC, I salute each and every one of you for making 1994 another incredible year for the NBCC. I wish that we could take some time to bask in the glory of our successes, but 1995 is already presenting us with new challenges which place some of our hard–earned accomplishments at risk.

As I write this letter, the $150 million we won this year to continue the Department of Defense (DOD) program is in trouble. The new Congress has targeted non-defense related items in the DOD budget, and some key committees have already stated that they consider the breast cancer research program one of the items that should be rescinded. Inside this issue of *Call to Action* you will find an action alert. Add your voice and the voices of everyone you know to demand that Congress protect the DOD breast cancer research program.

I'd like to give you a sense of how successful this program has been. A couple of months ago I visited a leading non-profit, private research institute to hear about their breast cancer projects. There I met a scientist, a viral immunologist, who told me that she had never thought about doing research in breast cancer, until she read about the DOD program. She applied for a grant, received the highest score possible and is now researching the possibility of a vaccine for breast cancer. Think about it — that research is going on right now because of you — the DOD program would not exist but for NBCC and NBCC would not exist but for you.

While today breast cancer receives more and more attention we still do not have more of the answers that we seek. The first years of NBCC's existence were devoted to increasing the dollars allocated for breast cancer research. We then moved to establish the National Action Plan on breast cancer. But our work becomes more difficult each year as the issues become more complex. Our activism now must spread beyond Congress to the scientific community and within private industry. While we extend the reach of our activism we must continue to push for more dollars, for more accountability within NCI and must make certain that the National Action Plan is implemented as intended. We must broaden our scope beyond the National Cancer Institute and begin to focus on the Food and Drug Administration and the Environmental Protection Agency. We have an ambitious legislative agenda for 1995 that is described within these pages.

I am often asked how we have accomplished so much in so short a time. My answer is that it has not been easy, that it has been accomplished by incredible sacrifices, hard work and commitment of the thousands of women and men across the country who make up the NBCC. At the beginning of the new year I ask that you again commit yourselves to this battle, so that we can continue to achieve the seemingly impossible and soon end this epidemic.

Fran Visco, President

The National Breast Cancer Coalition
A grassroots advocacy effort

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Fran Visco, President

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Volume 1
Number 3
Fall 1994

Call to Action

THE QUARTERLY NEWSLETTER OF THE NATIONAL BREAST CANCER COALITION

NBCC President Fran Visco and board member Dr. Susan Love thank President Clinton, Secretary Shalala and Hillary Clinton for responding to our petition campaign and agreeing to create a National Action Plan on breast cancer.

Dear Activists:

In the Fall of 1991, the Board of Directors of the NBCC met in Philadelphia at my law firm. The discussion was intense — we were debating how much money to demand that Congress appropriate for breast cancer research. We were unanimous on one point — we had no intention of lobbying for more money to simply hand over to the National Cancer Institute. We wanted a plan for how that money would be spent and a seat at the table. We were determined to get a national commitment to our issue — a collaboration, a strategy to end this epidemic. We decided to call for involvement of all segments of society, consumers, activists, science, providers, industry, media and government.

In the last issue of *Call to Action* you read about NBCC's tremendous accomplishments in Campaign '93 which resulted in the creation of the National Action Plan on breast cancer. This issue focuses on: the specifics of the plan, what has happened to date, and how you can help get this plan implemented.

For those of you who are new to the Coalition, the Plan was a result of the success of Campaign '93 — NBCC's effort to collect 2.6 million signatures on a petition to President Clinton demanding a coordinated, comprehensive strategy to end the breast cancer epidemic. The campaign not only raised awareness of the reality of breast cancer but also helped to develop support beyond our own grassroots network for our plan. And, when President Clinton said yes to our demands, we reached a major milestone along the path to our goal.

The National Action Plan outlines action steps to be taken in the areas of health care, research, and policy. Each of these action steps provides opportunities to advance and apply knowledge about the causes, diagnosis, prevention, treatment and ultimate eradication of breast cancer. The Plan also requires that the public, private, and non-profit sectors work together.

As you read this issue of "Call to Action," remember — the National Action Plan exists because of you — our supporters our members, our activists. Our success has been a joint venture from the beginning and we must continue together if we are to achieve the ultimate goal of ending the breast cancer epidemic. I am very proud of the National Action Plan. It is the first ever comprehensive strategy to address the breast cancer epidemic, and it would not exist today without our insistence that the nation focus attention on this devastating epidemic.

Fran Visco, President

The National Breast Cancer Coalition
A grassroots advocacy effort

The National Breast Cancer Coalition Fund
a grassroots advocacy effort

P.O. Box 66373
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CONGRESSIONAL FORUM SERIES

A Briefing on the Department of Defense Breast Cancer Research Program

Program

February 22, 1995
11:30 a.m. -- 1:00 p.m.
Rayburn House Office Building, Room B-339

Congressional Sponsor -- The Honorable Barbara Vucanovich

11:45 a.m.	*Fran Visco*, President, National Breast Cancer Coalition -- Introduction
11:50 a.m.	*The Honorable Barbara Vucanovich* -- Welcome and Remarks
Noon	*Fran Visco* -- Remarks
12:10 p.m.	*Irene M. Rich, DNSc., Colonel, Army Nurse Corps*, Director U.S. Army Breast Cancer Research Program, U.S. Army Medical Research and Materiel Command -- Overview of Program
12:30 p.m.	*Dennis J. Slamon, M.D., Ph.D.*, Chief, Division of Hematology/ Oncology, UCLA School of Medicine* -- Implications of Basic Biology Research in the Diagnosis and Treatment of Breast Cancer: A Practical Example
12:50 p.m.	Adjourn

* Dr. Slamon is the Director of the Revlon/UCLA Women's Health Research Program and was a recipient of a grant from the 1993-1994 U.S. Army Breast Cancer Research Program.

The National Breast Cancer Coalition (NBCC) is a grassroots advocacy organization dedicated to the eradication of the breast cancer epidemic. Founded in 1991, NBCC has a membership of more than 270 organizations and 27,000 individuals, representing several million patients, professionals, women, their families and friends.

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CONGRESSIONAL FORUM SERIES

The National Breast Cancer Coalition (NBCC) is a grassroots advocacy organization whose goal is the eradication of breast cancer. Founded in 1991, NBCC currently has over 300 member organizations and tens of thousands of individual members. Our nationwide membership includes a network of breast cancer advocates in every state. NBCC has:

-- successfully fought for a more than fivefold increase in federal funds for breast cancer research;
-- brought about an unprecedented peer reviewed breast cancer research program in the Department of the Army;
-- targeted President Clinton with 2.6 million signatures which resulted in his commitment to create a National Action Plan to end breast cancer;
-- established collaborative relationships with leaders in the scientific and medical community and become part of the research decision making process.

Despite the successes of NBCC and increased attention to the breast cancer epidemic, the incidence of breast cancer continues to rise. We still do not know how to prevent this disease or how to cure it. Today, there are 2.6 million women living in this country with breast cancer; this year 182,000 women will be diagnosed and 46,000 will die of the disease.

Breast cancer is a complex disease. It presents a number of difficult issues, many of which require congressional response. The science on which that response must be based is often far from clear. New discoveries, ongoing research and the epidemic proportions of the disease create an almost constantly changing backdrop against which breast cancer policy must be determined.

The National Breast Cancer Coalition is committed to a partnership with the scientific community and policymakers in a coordinated effort to eradicate breast cancer. An integral part of our mission is to assist policymakers to make informed decisions about breast cancer. To further that goal, NBCC will hold a series of Congressional Forums on Breast Cancer. Each forum will have experts address a specific breast cancer policy issue, present the science that drives the need for the policy and give a constituent perspective on the issue. When there are diverse views among the scientific or lay community on a particular issue, our forums will present this diversity and facilitate discussion.

Our goal is to help members of Congress and their staff acquire up to date information about breast cancer and to report on research discoveries that impact policy. Topics will include, for example, a briefing on the Department of the Army Breast Cancer Research Program, the privacy and insurance implications of the discovery of a breast cancer gene, the controversy over mammography screening for women under fifty; the drug approval process; environmental links to breast cancer; and the future of the research gold standard - clinical trials.

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History • Goals • Accomplishments

The National Breast Cancer Coalition (NBCC) is now a forceful voice, speaking for women and men across the country, who are demanding victory in the war against breast cancer.

The National Breast Cancer Coalition is a grassroots advocacy effort conceived in January 1991. Since that time, the Coalition has grown to more than 250 organizations, representing several million patients, professionals, women, their families, and friends. Coalition members include cancer support, information, and service groups, as well as women's, consumer health, and provider organizations. Thousands of individuals are members of the Coalition's National Action Network.

In just under three years, the NBCC has had a significant impact on general awareness about the breast cancer epidemic, and has had a major influence on public policy. We were able to achieve this success through intensive work and participation on the part of the NBCC Board of Directors, Task Forces, member organizations and our national grassroots action network.

The mission of the National Breast Cancer Coalition is to work to eradicate breast cancer, the most common form of cancer among women in the United States, through focusing national attention on breast cancer and by involving patients and caring others as advocates for action, advances and change. The Coalition informs, supports, and directs patients and concerned others in knowledgeable and effective advocacy efforts. Nationwide, women and men are bringing about meaningful progress in breast cancer policy through legislative and regulatory input, promotion of media coverage, and participation in activities such as marches and campaigns.

The goals of the National Breast Cancer Coalition are • to promote research into the cause of, optimal treatments and cure for breast cancer through increased funding, recruitment, and training of scientists and improved coordination and distribution of research funds • to improve access to high-quality breast cancer screening, diagnosis, treatment, and care for all women, particularly the underserved and uninsured, through legislation and change in the regulation and delivery of breast health care • to increase the involvement and influence of those living with breast cancer in the areas of legislation, regulatory process, and all aspects of clinical trial design, including access to clinical trials.

Accomplishments

- The NBCC "Do the Write Thing" letter campaign set out in October 1991 to deliver 175,000 letters to Congress and the President -- one letter for each projected breast cancer diagnosis that year. In an extraordinary demonstration of the grassroots power of this issue, we delivered more than 600,000 letters. This outpouring of letters plus hard work by NBCC members resulted in an appropriation of $132 million for breast cancer research to the NCI in fiscal year 1992 -- a gain of almost 50% over 1991 spending.

- In February 1992, the NBCC convened Research Hearings in Washington. Fifteen of the nation's most prominent scientists working in the field of breast cancer testified. As a result of the Hearings, the Coalition told Congress that 300 million additional dollars would be needed in 1993 for breast cancer research.

- During Mother's Day weekend of 1992, the NBCC coordinated 38 events in 31 states to emphasize the need for more research dollars for breast cancer, quality assurance in mammography, and a national registry system.

- In July 1992, the NIH reauthorization bill that included the NBCC's figure of $300 million for breast cancer passed the House and Senate, only to be vetoed by President Bush.

- Led by the NBCC, women arrived in Washington by the busload and swamped their members of Congress with calls, faxes, telegrams through the NBCC hotline and constituent visits demanding $300 million more for breast cancer research.

- The NBCC's demands were met. We won more than $400 million for breast cancer research: $210 million in the Department of the Army and $200 million to the National Cancer Institute. This total appropriation comprises the first-ever significant increase in breast cancer research funding.

- We endorsed or supported the Mammography Quality Standards Act of 1992, a Sense of the Senate Resolution Declaring Breast Cancer a Public Health Emergency, the Cancer Registries Act of 1992, and the Breast and Cervical Mortality Prevention Act of 1990.

- The Coalition increased the visibility of breast cancer as a national health emergency. NBCC leaders met with Hillary Clinton during the presidential campaign to brief her on breast cancer issues. We appeared on "The Today Show", CNN's "Sonya Live" and the "ABC Nightly News", and were covered by "U.S. News and World Report", "The New York Times Sunday Magazine" and dozens of national and local publications.

- On May 2-4, the NBCC kicked off its 1993 Campaign to secure 2.6 million letters, postcard, signatures, faxes and mailgrams directed to President Clinton asking that the breast cancer epidemic be declared a National Health Emergency and that we develop a National Strategy to end the epidemic.

- Over the following six months, Coalition volunteers across the country spread out to collect the 2.6 million signatures; they stood in front of supermarkets, in their churches, synagogues, in schools, at county fairs, at their workplace, wherever they could get signatures and raise awareness about this issue.

- On October 18, 1993, more than 1,000 Coalition supporters marched from the National Museum of Women in the Arts to the Ellipse, behind a Coalition banner with the message "End the Breast Cancer Epidemic", while more than 200 Coalition members met with President Clinton, Hillary Rodham Clinton and Secretary Donna Shalala, in the East Room of the White House, to present the signatures. Following the White House ceremony, the Coalition held a rally on the Ellipse at which entertainers, Coalition members and members of Congress spoke.

- In response to the Coalition's demands, President Clinton asked Secretary Shalala to host a conference to begin the design of a national action plan for breast cancer. On December 14, 1993, Coalition members, other breast cancer advocates, members of Congress, of the Administration, of the scientific community, private industry and the media came together to begin sharing ideas and reaching consensus on the elements of a strategy to end breast cancer.

In summary, in less than three years, the National Breast Cancer Coalition has:

- increased the funding for breast cancer research more than fourfold -- from $90 million to more than $410 million;

- Created a grassroots network across the country of women and men who are committed to this issue;

- heightened awareness through two nationwide signature campaigns, collecting 600,000 and then 2.6 million signatures demanding attention to breast cancer;

- brought the issue to the East Room of the White House and the level of the Presidency of the United States;

- precipitated the development of a National Action Plan on breast cancer that will be a collaboration of government, private industry and consumers;

- helped plan the conference hosted by Secretary Shalala to bring about that action plan and draft the action plan itself;

- become a driving force within the scientific community and changed the focus of research, and;

- precipitated the development of an unprecedented $210 million breast cancer research project within the Department of Defense that has attracted close to 3,000 proposals

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FACTS ABOUT BREAST CANCER IN THE U.S.

- Breast cancer is the most common form of cancer in American women. It rarely occurs in men. An estimated 2.6 million women in the U.S. are living with breast cancer: 1.6 million who have been diagnosed and an estimated 1 million who do not yet know they have the disease.

- One out of eight women in the United States will develop breast cancer in her lifetime -- a risk that was one out of 14 in 1960. This year, a new case of breast cancer will be diagnosed every three minutes, and a woman will die from breast cancer every 12 minutes.

- In 1993, approximately 182,000 new cases of breast cancer will be diagnosed and 46,000 women will die from the disease.

- We do not know what causes breast cancer or how to cure it. Women with breast cancer are dying at the same rate today as they did in the 1930s, and the same basic methods of treatment are being used: surgery, chemotherapy and radiation.

- Since 1960, more than 950,000 U.S. women have died from breast cancer (with 48% of those deaths occurring in the last ten years). This is more than two times the number of all American combat deaths from World Wars I and II, the Korean, Vietnam and Persian Gulf wars combined.

- Thirty-eight percent of African American women with breast cancer will not live more than five years, and 25% of white American women with breast cancer will not live more than five years. Forty percent of all women with breast cancer are dead within ten years.

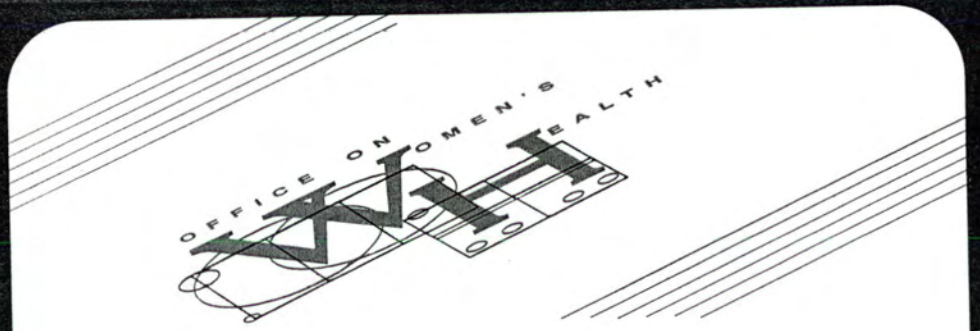
- Every woman is at risk for breast cancer. The risk of developing breast cancer increases as a woman ages, if she has a family history of breast cancer, has never had children or had her first child after age 30. Most breast cancer (over 70%), however, occurs in women who have no identifiable risk factors.

- Breast cancer is the leading cause of death for women 40-44 and the leading cause of cancer death in women 15-54. Incidence of breast cancer increases with age, rising sharply after age 40. Eighty percent of all breast cancers occur in women over 50.

- Mammography does not prevent or cure breast cancer, it can only detect it "early". In this context, "early" means that the tumor can be there for six to ten years before it is detected by mammography.

- Only about 40% of American women follow the recommended guidelines for screening mammography, a simple procedure that can reveal small breast cancers up to two years before they can be felt.

- Most breast irregularities are found by women themselves, yet many women do not know how to perform breast self-examination and few do so regularly.



NATIONAL ACTION PLAN FOR BREAST CANCER

STEERING COMMITTEE MEETING

February 13, 1995

PHOTOCOPY PRESERVATION

U.S. PUBLIC HEALTH SERVICE
OFFICE ON WOMEN'S HEALTH

U.S. DEPARTMENT OF HEALTH
AND HUMAN SERVICES

National Action Plan on Breast Cancer
Progress Report

Background

Breast cancer, the most commonly diagnosed cancer and the second leading cause of cancer deaths among American women, has been identified as a public health priority in the United States. Breast cancer represents 32 percent of all cancers in women, and the lifetime risk of developing breast cancer today is one in every eight women, up from one in every twenty women just two decades ago.

In October 1993, President Clinton was formally presented with a petition signed by 2.6 million people calling for the establishment of a comprehensive strategy to end the breast cancer epidemic. The Department of Health and Human Services (HHS) was asked to respond, and, in December 1993, HHS Secretary Shalala convened the *Secretary's Conference to Establish a National Action Plan on Breast Cancer*. The conference was a unique undertaking that brought together for the first time 300 individuals, including advocates, consumers, clinicians, scientists, government officials, educators, members of Congress, the media, and others to develop a comprehensive plan for fighting breast cancer.

The **Proceedings of the Secretary's Conference to Establish a National Action Plan on Breast Cancer** provides a framework and plan for activities in three major areas: the delivery of health care, the conduct of research, and the enactment of policy. The recommendations reflect areas of shared concern, pairing scientific knowledge and expertise with social insights and advocacy to achieve a single goal. The document represents a statement of national opportunities upon which to build and strengthen knowledge, resources, and commitment in the prevention, diagnosis, treatment, care, and, ultimately, elimination of breast cancer as a threat to American women. Many of the action steps outlined in the document are being realized with the creation of public/private partnerships among consumers, health care professionals, scientists, private industry, Congress, the media, and Federal and state government agencies.

All Federal activities related to the goals and action items in the Plan have been compiled into two inventories, one that reflects activities for the HHS, and one for the Federal agencies outside of HHS.

Organization

Susan J. Blumenthal, M.D., M.P.A., Deputy Assistant Secretary for Women's Health, and Frances Visco, Esq., President of the National Breast Cancer Coalition, a major grassroots advocacy organization, co-chair the **National Action Plan on Breast Cancer** (NAPBC) and coordinate its implementation.

Since December 1993, substantial progress has been made in implementing the action plan. The Conference Co-Chairs Coordinating Group has identified six priority actions and has formed working groups to implement the priorities over the next year. In addition, a group of representatives from the HHS agencies and another made up of representatives from Federal agencies outside of HHS are sharing information on breast cancer activities in the government that address the goals of the NAPBC and are providing guidance on areas that need attention and action. All of these groups are stimulating collaborations and new initiatives and working to ensure that the major players nationwide integrate their actions and work.

Progress to date on the NAPBC priority actions is summarized below.

Conference Co-Chairs Coordinating Group

In June 1994, the Conference Co-Chairs Coordinating Group met with government representatives and set six major priorities for the NAPBC:

Information Superhighway: Identify strategies to disseminate information about breast cancer and breast health to scientists, consumers, and practitioners using the state-of-the-art technologies available on the *information superhighway*.

National Patient Data Registry: Establish biological resource banks and comprehensive patient data registries to ensure a national resource of information for multiple areas of breast cancer research.

Consumer Involvement: Ensure consumer input at all levels in the development of public health and service delivery programs, research studies, and educational efforts. Involve advocacy groups and women with breast cancer in setting research priorities and in patient education.

Breast Cancer Etiology: Expand the scope and breadth of biomedical and behavioral research activities related to the etiology of breast cancer.

Clinical Trials: Make clinical trials more widely available to women with breast cancer and women who are at risk for breast cancer. Decrease barriers to participation through consumer-clinician dialogue, reduction of economic barriers, and other strategies.

Breast Cancer Susceptibility Gene: Implement a comprehensive plan to address the needs of individuals carrying breast cancer susceptibility genes and recommend educational interventions for consumers, health care providers, and at-risk patient groups.

For each of these priority areas, a planning group was formed to identify participants for longer-term working groups and to outline the issues these groups should address. The role

of the working groups is to define implementation strategies within the context of their priority area, identify resources needed for implementation, and develop time-lines to guide activities. Each group has a co-chairperson from the public and private sector. Formation of these groups and their working plans will be completed in the first quarter of 1995. The Fiscal Year (FY) 1995 budget to fund activities related to the NAPBC is $10 million.

Planning Group Activities

The **Information Action Council Planning Group** considered how the Information Superhighway can improve access to information about breast cancer and breast health for consumers, scientists, and practitioners to promote detection, diagnosis, and treatment of breast cancer. The group met with industry leaders, consumers, and government representatives to develop an outline of what needs to be done to address the issues and to develop a set of overarching questions for the working group to consider. A variety of organizations were consulted, including Bell Atlantic, America Online, the Maryland Division of Library Development Systems, the Georgetown University Medical Center for Imaging Science and Information Systems, the U.S. Army Advanced Research Projects Agency-Advanced Technologies and Telemedicine, the U.S. Department of Commerce, and the Federal Communications Commission. The planning group identified short- and long-term issues for the working group to address, including telemedicine opportunities on the information superhighway such as performing mammography or biopsy at a rural site and transmitting images to an urban medical center for interpretation and interactive capabilities in the home to get breast education and consult with health care providers.

The **Comprehensive Data Registries and Materials Planning Group** focused initial efforts on the development of a national biological resource bank and comprehensive patient data registry for breast cancer tissues. In conjunction with the National Cancer Institute (NCI), the planning group sponsored a national meeting in September 1994 to discuss currently available resources and ethical, legal, and technical issues associated with creating a data bank. Breast cancer advocates and scientists were among the 85 participants who convened to discuss the availability of breast cancer tissue and patient data for use by researchers across the nation. The working group will consider recommendations made at the meeting when determining future strategies in this critical area.

The **Planning Group to Ensure Consumer Involvement** addressed the issue of obtaining consumer input at all levels in the development of public health programs, research studies, and clinical trials. This group discussed the importance of including/involving advocacy groups and women with breast cancer in setting research priorities and in patient education. As a first step, the members recommended that the working group review a list of all Federal committees and advisory boards that address breast health activities to determine if consumers/advocates are represented.

The **Breast Cancer Etiology Planning Group** has had several conference calls and has initiated a review of research related to the causes of breast cancer that is currently funded by

the National Institutes of Health, the Department of Defense, and other organizations. The effects of environmental influences are a high priority. Plans are underway to obtain comparable information regarding ongoing breast cancer etiology research supported by private foundations and by some states, such as California, New York, and Massachusetts. In September 1994, the Interagency Working Group on Breast and Gynecologic Cancers (coordinated by NCI) sponsored a workshop on current research on the causes of breast cancer.

The **Availability of Clinical Trials Planning Group** discussed ways to ensure that clinical trials are more widely available to women with breast cancer and to women at risk for this disease. The group will recommend actions that will reduce barriers to participation in treatment and prevention trials, including consumer-clinician dialogue and easing economic burdens. Availability of trials and access to these trials will also be an important focus of the working group.

The **Breast Cancer Susceptibility Gene Planning Group** has had two conference calls and recommended that the working group review the Task Force reports of the Human Genome Project on the protection, use of information, and counseling recommendations for genetic/molecular testing. The planning group also recommended that the working group review current research efforts and make recommendations regarding future research initiatives and identify educational interventions for consumers, patients at risk, and health professionals.

Additional Federal Activities

HHS Coordinating Group

This group, which is comprised of agencies from the HHS, met in the Spring of 1994 and identified issues to address in the coming year. Priorities in the area of health care include programs to expand both public and private breast health services to all women, particularly underserved populations, and the publication of a breast health resource directory, a registry of ongoing and published clinical trials, and an inventory of proven strategies to increase breast cancer screening. The HHS Coordinating Group will interface with the working groups.

Federal Agencies Coordinating Group

For the first time, fourteen Federal Agencies have joined together to develop a coordinated strategy to fight breast cancer. Three working groups are organizing to address Access/Outreach in each agency's own programs, Comprehensive Breast Cancer Data Registries, and Environment and Breast Cancer Research. The Access/Outreach group met to discuss common issues and identify more effective ways to provide breast health information to women served by each agency. Examples of Federal agency efforts include:

The Department of Veterans Affairs is considering offering screening mammography for low-income women veterans and may need legislative action to implement the coverage.

The Department of Housing and Urban Development is exploring how it can facilitate providing breast cancer information and programs to older women residing in housing projects.

The Department of Defense has provided $200 million of support for new research on breast cancer with a particular focus on increasing knowledge about the causes of this disease.

Future Plans

In 1995, NAPBC participants will consider a range of activities and strategies to further the plan's implementation with an emphasis on developing strong public and private partnerships. Also, $10 million is allocated to support the priority action items of the NAPBC. In early February 1995, a Steering Committee will meet to refine implementation of the NAPBC and develop guidelines for the working group process.

January 1995

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Proceedings

Secretary's Conference to Establish a National Action Plan on Breast Cancer

National Institutes of Health
Bethesda, MD
December 14-15, 1993