NATIONAL PLAN OF ACTION ON ASIAN AMERICAN WOMEN AND BREAST CANCER

NATIONAL ASIAN WOMEN'S HEALTH ORGANIZATION

MAY 1997

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ACKNOWLEDGMENTS

NAWHO would like to gratefully acknowledge the following sponsors of our mission to eradicate breast cancer by involving Asian American women at every level of the fight against this devastating disease:

Bristol-Myers Squibb, Co., Oncology/Immunology
The Susan G. Komen Breast Cancer Foundation
✓ **Office of Minority Health, Department of Health and Human Services**
Office on Women's Health, Department of Health and Human Services
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for co-sponsoring the first National Asian American Breast Cancer Summit and Follow-up Meeting

We would also like to thank the following additional foundations for their generous support of NAWHO's Asian American Women's Breast and Cervical Cancer Project:

The San Francisco Foundation
California Community Foundation
Contra Costa County Breast Cancer Partnership
The Breast Cancer Fund

Finally, NAWHO would like to give special thanks to the **National Breast Cancer Coalition** (NBCC) and the **American Cancer Society** (ACS) for their generous support and technical assistance on the National Plan of Action on Asian American Women and Breast Cancer and the Asian American Women's Breast and Cervical Cancer Project.

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GROUP ON CHINA, CHAIR

AT LARGE WHIP

April 1997

National Asian Women's Health Organization
250 Montgomery Street, Suite 410
San Francisco, California 94104

Dear Friends:

I am pleased to endorse the National Asian Women's Health Organization (NAWHO)'s National Plan of Action on Asian American Women and Breast Cancer. I would like to thank the individuals who were involved in the plan's development. NAWHO is to be commended for producing such a groundbreaking document.

We must work together to combat what is a leading cause of mortality in Asian women. With your help, I am confident that NAWHO can build upon the recommendations in the action plan to address the health care needs of Asian women.

I urge our country's community leaders, scientific and medical communities, and policy makers in government, industry, and research to join with NAWHO in combatting this serious health problem. I pledge to continue to do what I can in working with my colleagues in Congress and with the Administration on this issue. I look forward to the Congressional Forum that NAWHO will be sponsoring in the fall of this year.

Working together, we can meet the challenges ahead as we entry the 21st century. My best wishes as you come together at NAWHO's national conference on Asian women's health.

Sincerely,

Nancy Pelosi

NANCY PELOSI
Member of Congress

National Asian Women's
Health Organization

Dear Friends,

On behalf of the National Asian Women's Health Organization (NAWHO), I am proud to present the National Plan of Action on Asian American Women and Breast Cancer. This document is the result of a historic collaboration between breast cancer experts who came together to support NAWHO in an endeavor to involve Asian American women at every level of the fight against breast cancer.

Changing demographics and immigration dictate the need for a new perspective. As women move from Asian countries with low breast cancer incidence and mortality rates to the United States, their risk of breast cancer increases. This risk then increases with each successive generation living in the U.S. In addition, the diversity of the Asian American population blankets the fact that for some ethnic subgroups such as Japanese Americans and Chinese Americans, the rates almost equal those of white American women.

The complexity of women's physiology demands more extensive research and scientific knowledge about women's health, and the fact that women are still dying from breast cancer brings a powerful urgency to this need. Breast cancer is not merely another disease, it is a quality of life issue that severely affects women both physically and emotionally, in their working lives, and in their homes. We can no longer allow any woman to feel devastated, alone, or hopeless when she is diagnosed with breast cancer. There must be treatment, and there must be a cure.

It is our vision that more Asian Americans will become active in this endeavor; that this new and powerful Asian American advocacy will contribute toward a faster end to the breast cancer epidemic, and improve the quality of life for all women.

Sincerely,

Mary Chung

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Executive Director

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AMERICAN CANCER SOCIETY

AMERICAN CANCER SOCIETY

The American Cancer Society (ACS) is pleased to support the National Asian Women's Health Organization (NAWHO) and the National Asian American Breast Cancer Plan of Action. We congratulate NAWHO for their leadership in developing this plan of action, and are grateful for the invitation to participate in the discussions they sponsored with other organizations to establish the foundation for this document. Through continued collaboration, the organizations who participated in the development of the plan, as well as others with a commitment to Asian American women and breast cancer, can make progress on this important issue.

The goals of the action plan are consistent with the mission of ACS, and we look forward to future opportunities to join NAWHO in raising awareness about the needs of Asian American women, and working to build public health infrastructure to meet those needs. The American Cancer Society is the nationwide community-based voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives and diminishing suffering from cancer, through research, education, advocacy and service.

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NATIONAL PLAN OF ACTION ON ASIAN AMERICAN WOMEN AND BREAST CANCER

As part of the Asian American Women's Breast and Cervical Cancer Project, the National Asian Women's Health Organization (NAWHO), brought together leaders with expertise in breast cancer research, data collection, early detection, treatment, and advocacy to develop a comprehensive National Plan of Action on Asian American Women and Breast Cancer.

This Plan of Action is based on the information, strategies, and recommendations provided during the first National Asian American Breast Cancer Summit held in New York City on September 16, 1996, and the subsequent Follow-up Meeting held in Yountville, California on January 31, 1997. During the Summit, leaders in the fight against breast cancer discussed a number of innovative strategies to impact breast cancer in the Asian American community. The Summit participants identified four priority issues: addressing gaps in research and data; assuring that outreach and early detection programs are culturally and linguistically competent; improving accessibility of treatment programs; and increasing the involvement of the Asian American community in the nationwide effort to combat breast cancer.

During the Follow-up Meeting, experts offered their recommendations in the following specific areas: improving community-based intervention programs (screening, early detection, and treatment); building public and private partnerships; developing a better understanding of the etiology of breast cancer in Asian American women, including not only risk factors, but increasing intergenerational risk; increasing data collection on Asian American women; involving Asian American women in clinical trials; and expanding advocacy efforts to actively engage Asian American women. The National Plan of Action on Asian American Women and Breast Cancer incorporates these recommendations, and will be implemented by NAWHO and other agencies to increase the involvement of Asian American women in breast cancer research, outreach, education, and advocacy.

THE CHALLENGE

According to the United States Census Bureau, Asian Americans represent the fastest growing and most diverse ethnic groups in the United States. By the year 2020, the Asian American population will have increased from 8 million in 1992 to 20 million. Despite this growing presence, there have been few efforts to gather information and data on the more than 30 different ethnic groups who comprise the Asian and Pacific Islander community. Consequently, little is known about the specific health needs of this heterogenous population. This is especially true regarding breast cancer.

The lack of understanding about breast cancer in this community is complicated by the fact that Asian women living in the United States come from a variety of ethnic backgrounds, and have varying levels of English proficiency, cultural integration, and economic status. The specific health needs of Asian Americans have often been overlooked due to stereotypes, among the most misleading being the "model minority" myth, which perpetuates the impression that all Asian Americans are prosperous, educated, and healthy. This stereotype simply is not true for the vast numbers of Asians in the United States, and has masked the enduring barriers and problems that many Asian Americans encounter.

This lack of information and understanding translates into a lack of resources, services, and opportunities to meet the unique needs of Asian American women. The lack of extensive research on breast cancer and Asian American women also contributes to the inaccurate perception that all Asian American women are at lower risk for breast cancer compared with white American women. The Asian American community's own lack of health information and education, combined with the uninformed neglect of the medical community only reinforces the general notion that breast cancer is not a serious health problem in this community. For breast cancer in particular, this compounds the already pervasive problem of getting women to participate in screening programs, regardless of their socioeconomic or cultural backgrounds.

Cancer screening rates among Asian American women are very low. Asian and Pacific Islander women had lower rates of Pap test screening and mammography and clinical breast examination than any other United States racial or ethnic population in 1991-1992. A California study of 167 Chinese American women revealed that 69% reported no understanding of mammograms, while a survey of 1200 Vietnamese women in California found that 34% had never heard of mammography.

Changing demographics dictate the need for a new perspective on breast cancer in the Asian American population. While breast cancer incidence and mortality rates for Asian American women are the lowest of all women in the U.S., it is not possible to adjust these surveillance statistics on the basis of immigration status. Although breast cancer incidence and mortality rates are lower in Asian countries, and therefore lower among recent Asian immigrants to the U.S., this protective effect steadily errodes with each successive generation, and lifetime risk soon approaches that of white American women. Breast cancer incidence rates among Japanese and Chinese American women (Asian American ethnic groups with a majority having lived in the U.S. for three to five generations) are significantly higher than those of their counterparts in Japan and China. Thus, while it is true that incidence in the U.S. is lower in aggregate, four observations are critical to understanding the urgency of the problem faced by Asian American women. First, aggregate rates lead to stereotypes that are a poor basis for individual counseling; second, even though breast cancer incidence and mortality are lower, the disease burden in this population is not inconsequential. Third, the neglect of these problems will worsen over time as the population of Asian Americans grows into a larger group with a growing number of women who have equivalent risk of breast cancer. Lastly, the assumption of minimal disease burden contributes to diagnosis at stages with poorer prognosis.

We are concerned that the assumption that Asians do not get breast cancer may give Asian American women and the providers that serve them a false sense of security, and discourage breast cancer education and advocacy efforts for this population. It is clear that breast cancer educational and outreach methods have been less effective in reaching the Asian American population. It is critical that breast cancer information and services are provided to Asian Americans in a culturally and linguistically appropriate manner, and that health care providers, government officials, and researchers assist in shattering the myth of low breast cancer risk.

To work towards this goal, a comprehensive Plan of Action for systematically addressing all aspects of Asian American women's access to and involvement with breast cancer education and detection services is needed. This action plan will assist NAWHO and other agencies serving Asian Americans in catalyzing national efforts to advance research on breast cancer, improve accessibility to early detection and treatment programs for Asian American women, and encourage their participation and pro-active involvement in advocacy efforts.

NAWHO AND THE ASIAN AMERICAN WOMEN'S BREAST AND CERVICAL CANCER PROJECT

The National Asian Women's Health Organization (NAWHO) is a non-profit, community-based health advocacy organization committed to improving the overall health status of Asian women and girls. NAWHO was founded in response to the absence of comprehensive and pro-active research and services addressing the health issues of Asian women and girls, as well as the lack of programs promoting equality for and the self-empowerment of Asian American women.

NAWHO created the Asian American Women's Breast and Cervical Cancer Project in 1995, when participants at NAWHO's first national Asian women's health conference, "Coming Together, Moving Strong: Mobilizing an Asian Women's Health Movement " voiced their concerns about the need for a pro-active stance on breast cancer from the Asian American community. There was an obvious void in the growing nationwide fight against breast cancer, with little representation of Asian American women in mainstream efforts and little attention being given to breast cancer within the Asian American community itself. Hence, NAWHO began the Asian American Women's Breast and Cervical Cancer Project as an innovative and unique program that would address breast cancer and Asian American women at the community, medical, and public policy level.

In addition to convening the first National Asian American Breast Cancer Summit and Follow-Up Meeting, NAWHO has conducted regional training sessions for health care providers to improve outreach to the Asian American community in early detection and screening programs. These sessions are based on a training manual developed by NAWHO to assist providers and health educators in tailoring their current breast cancer programs to involve Asian American women. The sessions strive to encourage providers, clinicians, and health educators to become greater advocates for the health of Asian American women by increasing their awareness of Asian women's health needs and issues.

NAWHO is the only AsianAmerican organization serving on the Board of the National Breast Cancer Coalition, an advocacy group with over 50,000 individual members and 400 organizational members, that has helped raised millions for breast cancer research and an immeasurable level of heightened awareness about this devastating disease. In this NAWHO is bringing the voice of Asian Americans into the mainstream fight against breast cancer; working with a number of public and private sector agencies such as the Centers for Disease Control and Prevention and the American Cancer Society to ensure that the needs of Asian American women are incorporated into breast cancer research development, educational efforts, and treatment programs.

I. RESEARCH

A. EXAMINING INCREASE IN RISK AMONG ASIAN AMERICAN WOMEN

The epidemiology of breast cancer among Asian American women is linked to migration patterns. As women move to the United States from Asian countries, her chances of getting breast cancer increase, and the risk of breast cancer in successive generations increases as well. This increased risk among Asian American women and their daughters is presumably related to the loss of protective factors from low-incidence Asian countries and gain in risk for breast cancer associated with residence in the United States. However, very little is understood about the factors underlying this observation, and how they may vary by ethnicity and generation status. The heterogeneity of the Asian American population (i.e. ethnicity, generation status) poses a challenge to research investigations of breast cancer risk, but must not be neglected in study designs.

The lack of understanding regarding the specific etiology of breast cancer is no less complicated for Asian American women than for other U.S. women. For example, although differences in diet have been investigated, when studying dietary factors as risk factors for breast cancer among Asian American women, the influence of Asian cultural food staples are difficult to isolate, making it unclear whether a relationship is due to an actual biological connection or to other factors. Further, few studies have investigated the relative importance of well-established risk factors (e.g. menstrual/reproductive, family history) among Asian Americans. What is clear is that risk of breast cancer is lower in Asian countries than in the U.S., and when an Asian woman migrates to the U.S., her risk of breast cancer increases, and that increased risk is passed on to her daughter, and daughter's daughters until it is nearly equivalent to the average risk of other U.S. women.

RECOMMENDATIONS

- There must be more research aimed at identifying reasons for the increase of breast cancer in Asian American women, and more investigation of risk factor theories such as the differences associated with residence in the U.S. as compared to Asian countries. Researchers must work to ensure that differences (i.e. ethnicity, generation status) among subgroups of Asian Americans are examined and documented when conducting research on breast cancer.

- There must be more research on the comparative relevance of risk factors observed in white American women to Asian American women, taking into account the complexity and multi-factorial etiology of breast cancer (i.e., breast cancer is not a one-exposure disease). A better understanding of the lower risk for women residing in Asian countries, and the increasing risk over time after migration to the U.S., holds immense potential for understanding how breast cancer might be controlled. Thus, this research would benefit all women.

II. DATA COLLECTION

A. INCREASING AMOUNT AND ETHNIC SPECIFICITY OF BREAST CANCER DATA

Despite lower overall incidence and mortality rates, breast cancer still is the leading cause of cancer mortality for Asian American women. While national and state-based surveillance systems provide extensive amounts of data on white Americans, there are considerable gaps in the quality and coverage of comparable information on breast cancer in Asian American women, including age- and ethnic-specific information.

Lack of adequate data on Asian American women and breast cancer contributes to the misperception that Asians are not at risk for breast cancer. In turn, this may lead Asian American women to have a false sense of security about their own risk of breast cancer, and it may discourage funding for breast cancer education and advocacy efforts for this population.

Gathering ethnic- and generation- specific data is extremely important in order to gain an understanding of the epidemiology of breast cancer in Asian American women. For example, data from the National Cancer Institute's SEER Program indicate that between 1988 and 1992, the incidence of breast cancer among the Asian American population ranged from 29 per 100,000 for Korean American women to 82 per 100,000 for Japanese American women. Vietnamese Americans, Chinese Americans, and Filipino Americans had incidence rates of 38 per 100,000, 55 per 100,000, and 73 per 100,000 respectively.

Lack of adequate data systems contributes to the current inability to explain the differences in these rates. Also, little is known about the screening behavior of Asian populations.

RECOMMENDATIONS

Governments must strengthen their state and national capacity to carry out comprehensive programs to collect and use population-based data on breast cancer incidence and mortality among Asian Americans. Also, it is especially important that accessibility to services be regularly monitored. There is a critical need for reliable, comparable, and timely data on Asian American women. Data collection, analysis, and tracking must include ethnic subgroups of Asian American populations.

III. CLINICAL TRIALS

A. ADDRESSING ECONOMIC AND CULTURAL BARRIERS TO PARTICIPATION

The time required to participate in studies has a major impact on the recruitment and retention of Asian American women in clinical trials. Asian American women who work in hourly wage jobs economically cannot take the time off to participate in trials, nor to pay for the costs of any follow-up hospital or physician care not covered by the study. For many women, commitments to work, family, and their community often supersede any of their own health concerns. In addition, the health care providers that serve Asian Americans are not always aware of the availability of clinical trials for cancer patients, and are sometimes reluctant to refer a patient to new and experimental treatments over standard care.

RECOMMENDATIONS

- When recruiting for clinical trial participation among Asian Americans, researchers must design studies to take into account women's multiple roles and the demands on women's time, including child-rearing, household duties, and income-generating activities. When designing strategies for recruitment and retention of Asian American women in clinical trials, researchers must include the provision of follow-up care and referrals. In addition, there should be mechanisms available to cover follow-up physician and hospital fees that result from participation in clinical trials.

- Public and private sector agencies such as the National Cancer Institute and pharmaceutical companies should develop a strategy for involving the participation of Asian American women in clinical trials by working with Asian American community leaders and Asian American consumers in fostering a better public understanding and knowledge of clinical trials.

- Health care providers should communicate to patients the relative advantages and disadvantages of clinical trials in a culturally and linguistically appropriate manner, to allow patients to make an informed decision about their treatment options.

IV. TECHNOLOGY

A. ADVANCING SCREENING AND TREATMENT

Although early detection programs are now finding breast cancer at an earlier stage, methods of screening and treatment are invasive, potentially harmful in their use of radiation, and still do not detect breast cancer until 6-10 years into the course of the disease. Asian Americans are reluctant to utilize screening services because of the community's stigmatization of breast cancer as a fatal disease. Asian cultural norms treat such diseases as fate, as something that cannot be helped or fought against. The general fears of radiation and mastectomy, combined with the fact that many Asian Americans do not utilize any type of preventive care, contributes to breast cancer incidence in Asian American women found at later stages, creating an urgency for better treatment options.

The recent finding in breast cancer research of the BRCA1 and BRCA2 gene, whose mutations and alterations are found to increase a woman's lifetime risk of breast cancer, further complicates the issue of early detection and treatment for Asian American women. Although alterations in the genes are responsible for only 5% of all cases of breast cancer, its implications ranging from possible insurance discrimination, job discrimination, negative or positive psychological impact affect Asian American women significantly. Asian American women over the age of 65 have the highest suicide rate in the country, indicating a lack of psychosocial support structures for Asian American women. How will Asian American women deal with the depression and anxiety that may come from a positive test for the gene, which does not guarantee that a woman will get breast or cervical cancer? In addition, a negative test, which does not guarantee that a woman will not get breast or cervical cancer, may further reinforce the myth among Asian Americans that they are not at risk for breast cancer.

RECOMMENDATIONS

- While we encourage more Asian American women to utilize screening and early detection services, there is a critical need to work towards developing better screening technology and treatment options. There must be treatment that recognizes the justified concerns of the public toward radiation and mastectomy, in order to address the critical need of Asian American women with late stages of breast cancer.

- There must be legislative action to protect the consumer from discrimination, psychosocial risk, and misinformation. For Asian American women, this demands that issues of confidentiality, correct translation of information, and appropriate counseling be addressed. There has been a historical problem with informed consent and minority women, with clients not receiving adequate clinical information about the full range of services available. Since awareness of particular screening methods or treatment options and actual knowledge of their mechanism of action, availability, side effects, etc. are not always correlated, health care providers and health educators must identify effective strategies to ensure that Asian American women are fully informed and can demonstrate their understanding, particularly in the case of genetic testing.

V. GOVERNMENT AGENCY PROGRAMS

A. INCREASING AVAILABILITY OF TREATMENT OPTIONS

There is limited funding allocated to government programs to cover the breast cancer diagnostic and treatment services necessary to meet the needs of Asian American, as well as other under-served women.

Once a woman is diagnosed with breast cancer through the federally-funded National Breast and Cervical Cancer Early Detection Program (NBCCEDP), the legislation that authorizes the NBCCEDP does not permit payment for treatment services. However, many states are required by law to provide breast cancer treatment services for women when needed. For some Asian American women who may not be familiar with the health care system, navigating through a bureaucracy to obtain needed services and the necessary follow-up treatment in a timely manner is a problem.

RECOMMENDATIONS

- In order to be more comprehensive and meet the needs of all women, including Asian American women, government screening programs must include education, diagnostic, and treatment services.

- State programs must meet the legislative mandate to insure timely and appropriate breast cancer treatment for Asian American women, and work with community groups to ensure that women are aware of the process for obtaining these services.

B. ENSURING ACCESS

Access to existing government-sponsored programs offering breast cancer services and education is a critical need, particularly for under-served, non-English speaking women for whom these are the only services available.

When a woman comes in for a breast cancer screening, she may have symptoms for other illnesses. Although related categorical programs exist, providers at the breast cancer screening program may not know where patients can best access these services. For Asian American women who do not have high rates of utilization of health care services in general, this may be one of their few health care visits, and the only opportunity to be provided with health care for other problems.

RECOMMENDATIONS

- In order to reach under-served populations, government programs must work with local agencies in these communities. These programs must also raise physicians' and other health providers' awareness of issues concerning breast cancer within the Asian American community. Further, they must work to ensure that the rescreening of women for breast cancer is a priority among health care providers.

- Government programs should promote community participation in women's health services and decentralize management by forming partnerships with, and fostering the involvement of local Asian American community-based health organizations, private providers, and Asian American consumers.

- Government programs must ensure that their screening programs contain an education component which provides culturally-appropriate, accurate, and complete information on breast cancer to all clients, in order to empower women to seek preventive care, including the decision regarding when to begin having regular mammograms.

- Federal agencies, especially CDC and the National Institutes of Health (NIH), should set specific goals for the number of women they will provide services for in order to evaluate their effectiveness in reaching the Asian American population. In addition, they should support more ethnic-specific breast and cervical cancer health promotion and education programs.

- The availability of culturally-appropriate related health services, either on-site at government sponsored screening programs, or through a coordinated referral to public or private sector health care systems must be ensured.

- Government bodies such as the Office of Women's Health in the Department of Health and Human Services, must incorporate strategies on improving access provided by breast cancer and Asian American women's health advocacy groups into their policy programs, utilizing recommendations made at the 1996 "Bridging the Gap: Enhancing Partnerships to Improve Minority Women's Health" Conference, held in Washington DC January 27-28, 1997.

C. MANAGING RESOURCES

There is no mechanism to ensure that duplication of programs or services does not occur. This problem particularly affects Asian American populations where resources are scarce, and can ill-afford lack of access to a full range of care, from screening to treatment. Efforts must be taken to assure a more effective and comprehensive delivery of services when resources are scarce.

RECOMMENDATIONS

RECOMMENDATIONS

- In order to avoid duplication, government programs must maximize coordination of services and clarify responsibilities and roles of service providers so that under-served Asian American women can particularly benefit from redistribution and better allocation of breast cancer resources and services.

- There should be more collaboration across federal and state programs and organizations to help pool necessary resources to support projects that will improve the breast cancer outreach and screening/early detection services to Asian American women.

- More funding must be allocated to develop a template for health educational materials for Asian Americans, as well as to develop and maintain databases of existing educational materials. This resource would promote best practices and minimize duplication of effort.

VI. COMMUNITY-BASED INTERVENTIONS

A. IMPROVING OUTREACH TO ASIAN AMERICAN WOMEN

Among all U.S. racial and ethnic populations, Asian American women have the lowest rate of mammography screening. Data from the Behavioral Risk Factor Surveillance System show that in 1991-1992, only 48% of Asian American women aged 50 years and older reported having had a mammogram and clinical breast exam within the preceding two years. Although quality services exist, information is not being disseminated adequately enough in the Asian American community to affect screening behavior.

The low utilization rate of breast cancer screening methods among Asian American populations inevitably results in too many women being diagnosed at a later stage of disease. In addition, the allocation of culturally specific resources, such as breast cancer educational materials and services, for the Asian American population is difficult, due to the extreme ethnic diversity within the population.

Several cultural beliefs regarding health lead to delays in the diagnosis of breast cancer in Asian American communities. These include the stigmatization of breast cancer as a fatal disease, the belief in acceptance of fate and endurance of suffering, and not wanting to burden family members. NAWHO's past health assessments and recent health survey found that Asian American women's notions of health are shaped by the ways in which their roles are constructed in the family, community, and in the broader socioeconomic context. These roles have traditionally put women's health on the fringe, placing primary emphasis on the needs of men and the family as a whole.

RECOMMENDATIONS

- Asian American community leaders must become more involved in breast cancer outreach programs to ensure that information is reaching Asian American women. Asian American community-based clinics and organizations must break down the stigma surrounding breast cancer, emphasizing that diagnosis of breast cancer at a smaller size or earlier stage will give a woman more choices, and thereby a measure of control over treatment decisions. They must also promote women's health education and work to change the low priority status of Asian American women's health in their communities.

- More resources must be allocated to conduct community outreach on breast cancer screening to both non-English speaking, limited-English speaking and English speaking Asian American populations. Community outreach must include mass media campaigns, but also must consist of more than brochures and other health education materials. Many Asian American women get their health information from the media, such as women's magazines, but would prefer to receive more information from doctors and health educators. In addition, some women may be illiterate in their own Asian language or in English, and require verbal education.

- Asian American community health organizations must build stronger alliances with government-sponsored programs to ensure that they provide information on mechanisms for the follow-up and tracking of patients diagnosed with breast cancer.

B. IMPROVING DELIVERY OF SERVICES AND CARE

Breast cancer programs and services designed for the Asian American community that do not involve the participation of Asian Americans throughout the development process are often not culturally appropriate and do not adequately meet the needs of Asian American women. Further, many Asian immigrant and refugee women see health care providers who received medical training in Asia that did not emphasize clinical breast examinations or breast cancer screening services. Also, a significant number of Asian American women utilize traditional medicine in addition to western allopathic medicine. Physicians treating Asian American patients with breast cancer may not be aware of this fact, and may prescribe allopathic treatment without inquiring about traditional treatments.

RECOMMENDATIONS

- Model demonstration programs for addressing breast cancer in the Asian American community must be comprehensive, tailored to meet the specific needs of the local community, and include local and community leaders.

- Maintaining personal good health is not a cultural priority for Asian American women, and providers need to become advocates in changing a gender and culturally-based attitude toward preventive health care.

- Health care providers must be provided with the technical assistance necessary to increase breast cancer screening and referrals.

- There must be psychosocial support groups in place to assist Asian American women diagnosed with breast cancer, as well as for their families. In addition, more support mechanisms, such as a standard of care for counseling and education must be created in response to research developments such as the testing for the BRCA1 and BRCA2 genes.

- Programs and providers who serve Asian American women must recognize the importance and validity of traditional systems of medicine to Asian American women, and seek to understand and coordinate western and traditional systems of medicine.

VII. ADVOCACY

A. EMPOWERING ASIAN AMERICAN WOMEN

In order to improve access to quality health care, there is a constant need to monitor and shape the direction of public policy, the health care industry, and research efforts on breast cancer. However, Asian American women have been marginalized from participating in and influencing the political process that can improve health care in their communities. Asian American women must become involved and mobilize as a pro-active force to change the way health care institutions and programs have treated their issues and concerns.

RECOMMENDATIONS

Asian American leaders and breast cancer advocates must work together to educate Asian American women about the grassroots and public advocacy that can shape and improve health care delivery in the United States. They must also work together to increase their representation and inclusion in the leadership, planning, decision-making, management, and evaluation of services at all levels of the health care system.

The Asian American community must work to ensure that they are equipped with the knowledge and skills necessary to actively participate in public policy activities, advocate through the appropriations process, and educate state legislatures and the U.S. Congress by providing relevant and timely data and analysis relative to breast cancer.

The Asian American community should actively join the efforts of groups like the National Breast Cancer Coalition (NBCC) —which advocate within industry and the scientific and medical communities to bring the voice of women wherever decisions have an impact on the fight to eradicate breast cancer—to work in coalition to address breast cancer, as well as to ensure that the concerns of Asian American women are made a priority issue.

Advocates must work with policy-makers to ensure that funding is allocated for treatment services for low-income and under-served women with breast cancer, at the same time that advocates are promoting increased utilization of screening services among Asian American women. Advocates must also advocate for more funding towards improving the technology of screening and treatment methods.

VIII. PUBLIC AND PRIVATE PARTNERSHIPS

A. INCREASING COLLABORATION AND COORDINATION OF PROGRAMS

In 1993, after a massive drive, NBCC delivered 2.6 million signatures on a petition to the President of the United States resulting in his commitment to a National Action Plan on Breast Cancer (NAPBC) , a public/private partnership focusing on areas traditionally neglected in breast cancer. The successful planning and implementation of its activities depends on the sustained involvement of both the private and public sectors.

Coordination between government and non-governmental organizations, agencies, and individuals is necessary in order to identify and prioritize effective and pragmatic strategies to address diseases such as breast cancer.

RECOMMENDATIONS

- The NAPBC's Steering Committee must ensure that the Asian American community is represented at all levels of planning, implementation, and evaluation of the NAPBC, including representation on the Steering Committee. The NAPBC should incorporate the recommendations of the National Plan of Action on Asian American Women and Breast Cancer into the activities of the Working Groups. These Working Groups have been established to identify and implement specific initiatives within six priority areas identified by the Steering Committee. In addition to representation on the Steering Committee, Asian American women should also be included in the Working Groups, particularly with Consumer Involvement.

- Community women's health advocates should keep pharmaceutical companies informed of issues important to the Asian American community, in order to better direct research priorities and development of breast cancer treatment options. In turn, the pharmaceutical industry should recognize the mutual interests shared with Asian American community groups, and allocate more resources to the community to address those interests.

B. FOCUSING ON MANAGED CARE

Health care is rapidly changing to a managed care structure, with public and private partnerships becoming increasingly important to address the health needs of the diverse populations in the U.S. Again, ensuring appropriate care and coverage for a full range of services, including breast cancer screening, education, and counseling at any point of entry into the health care system is critical for Asian American women due to their low rates of utilization of preventive health care.

RECOMMENDATIONS

- Health care providers, government agencies, and community-based organizations should strengthen collaborative efforts with managed care institutions to ensure the availability of breast cancer screening, diagnostic, and treatment services for Asian American women.

- When Asian American women enter the health care system under managed care, breast cancer screening should be considered preventive health care and discussed by the primary care provider.

- Counseling and education programs on genetic testing should be made available in the range of Asian languages and presented in a manner that acknowledges the particular cultural views of the patient. While developing guidelines on issues such as BRCA1 and BRCA2, there must be mechanisms for enforcing guidelines and standards of care to ensure against genetic discrimination in health care coverage.

APPENDIX I

NATIONAL ASIAN AMERICAN BREAST CANCER SUMMIT AND FOLLOW-UP MEETING

List of Participants

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APPENDIX II

APPENDIX II

NATIONAL ASIAN AMERICAN BREAST CANCER SUMMIT

Congresswoman Nancy Pelosi (D-CA)
Honorary Chair

Mary Chung, Executive Director
National Asian Women's Health Organization
Convener

AGENDA

Monday, September 16, 1996, 10:00 a.m. - 3:00 p.m.
The Coleman Center
810 Seventh Avenue, 23rd Floor
New York, NY 10019

Discussion Moderator: **Cindy Pearson**, Executive Director
National Women's Health Network, Washington, DC

Session Moderators: **Mary Chung**, NAWHO
Alice Yaker, Executive Director of SHARE, NY

10:00 - 10:10 a.m.	Welcome	**Mary Chung**
10:10 - 10:20 a.m.	Introduction	**All Participants**
10:20 - 11:30 a.m.	Morning Session	**Moderator: Mary Chung**

OPENING KEYNOTE SPEAKER: **Susan J. Blumenthal, M.D., M.P.A.**
Deputy Assistant Secretary for Health
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Assistant Surgeon General
Co-Chair, National Action Plan on Breast Cancer

RESEARCH: **Otis Webb Brawley, M.D.**, Director
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PRIVATE/PUBLIC PARTNERSHIP: **Michael Loberg, Ph.D.**, President
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SCREENING AND OUTREACH:
Susan True, M.Ed., Acting Director
Bureau of Chronic Disease Services,
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MINORITY WOMEN'S HEALTH:
Tuei Doong, M.A., Deputy Director
Office of Minority Health, Dept. of HHS

11:30 - 12:00 p.m. Discussion **All Participants**

12:00 - 1:00 p.m. Luncheon

LUNCHEON KEYNOTE SPEAKER: **Congresswoman Nydia Velázquez (D-NY)**

1:00 - 2:00 p.m. Afternoon Session **Moderator: Alice Yaker**

SCREENING/EARLY DETECTION:
Steve Wyatt, D.M.D, M.P.H., Director
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ACCESS AND DATA COLLECTION:
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SURVIVOR:
Lucy Young, M.Ed., President
Chinese-American Cancer Association

ADVOCACY:
Pat Barr, Executive Board Member
National Breast Cancer Coalition

2:00 - 3:00 p.m Discussion **All Participants**

NATIONAL ASIAN AMERICAN BREAST CANCER SUMMIT FOLLOW-UP MEETING

AGENDA

Friday, January 31, 1997, 10:00 a.m. - 3:15 p.m.
Napa Valley Grille
6795 Washington Street
Yountville, CA 94599

Discussion Moderators:	**Mary Chung**, NAWHO **Sophia Chang, M.D., M.P.H.** Medical Director, San Francisco Health Plan	
10:00 - 10:10 a.m.	Welcome	**Mary Chung**
10:10 - 10:30 a.m.	Introductions	**All Participants**

RECOMMENDATIONS FOR PLAN OF ACTION
Morning Session
Moderated By: **Sophia Chang, M.D., M.P.H.**

10:30 - 10:50 a.m.	Examining Risk Factors for Asian American Women	**Anna Wu, Ph.D.**
10:50 - 11:10 a.m.	Data Collection on Asian American Women	**Laura Greiner** **Howard Koh, M.D., M.P.H.**
11:10 - 11:30 a.m.	Involving Asian American Women in Clinical Trials	**Laurel Eu, M.A.**
11:30 a.m. - 12:00 p.m.	Profile of Government Agency Programs	**Rosemarie Henson, M.S.S.W., M.P.H.** **Cora Yamamoto, M.S.S.W.**
12:00 - 12:40 p.m.	LUNCH	**NAWHO Overview and Presentation**

RECOMMENDATIONS FOR PLAN OF ACTION
Afternoon Session
Moderated By: **Mary Chung**

12:40 - 1:20 p.m	Profiles of Government Programs (continued)	**Tuei Doong, M.H.A.** **David Ginsburg, M.P.H.** **Kate Monico Klein** **Christina Perez** **Kay Strawder, JD, M.S.W.**
1:20 - 2:00 p.m.	Community-Based Interventions: Screening, Early Detection, and Treatment Services	**Linda Frame** **Priya Jagannathan, M.P.H.** **Lillian Lew, M.Ed., R.D** **Rod Lew, M.P.H.** **Evaon Wong-Kim, M.S.W.**
2:00 - 2:30 p.m.	Advocacy and the Breast Cancer Movement in the United States	**Fran Visco, J.D.** **Amy Allina**
2:30 - 3:00 p.m.	Building Public and Private Partnerships	**Debra Nakatomi** **Carol Noblitt** **Kathleen O'Donnell**
3:00 - 3:15 p.m.	Closing Remarks and Discussion	**Mary Chung** **All Participants**