

**ADDENDUM TO
REPORT TO CONGRESS**

**CDC Review of the Northern California Cancer Center Report:
“Status of Breast Cancer Research in the San Francisco Bay Area”
Summary of Public Comments**

Centers for Disease Control and Prevention

September 13, 1999



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service



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Section 1: Public Meeting Speaker and Community Panel Listing

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**Section 2: Community Meeting - San Francisco, CA September 1, 1998-
Sign In Sheet**

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Thoa Nyugen	Vietnamese Community Health Promotion Program
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Janet McDonald	U.S. Food and Drug Administration, San Francisco District Office
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Eva Glazer	California Department of Health Services
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Tina Clarke	Northern California Cancer Center
Tama Greenberg	
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Linda Richardson	Southeast Alliance for Environmental Justice
Jennifer Stoll-Hadayia	National Asian Women's Health Organization

Section 3: Public Questions and Comments on CDC's Review of the Northern California Cancer Center (NCCC) Status Report

In October 1997, CDC began collaborating with NCCC and the California Department of Health Services (CDHS) to review breast cancer incidence and mortality rates for women living in the San Francisco Bay Area. As a result of this effort, NCCC in conjunction with CDHS released a report entitled "The Status of Breast Cancer Research in the San Francisco Bay Area." The Status Report presents recent data regarding trends in breast cancer incidence in the San Francisco Bay Area and highlights recently completed projects investigating breast cancer incidence. It also provides summaries of the 40 individual research projects related to breast cancer incidence in the San Francisco Bay Area and elaborates on future potential projects that could improve and enhance our understanding of breast cancer.

CDC reviewed the Status Report prepared by NCCC, consulted scientific literature on breast cancer and environmental factors, and independently analyzed breast cancer incidence rates in the San Francisco Bay Area from 1973-1994. CDC's findings and recommendations were included in the report *CDC Review of the NCCC Report: "Status of Breast Cancer Research in the San Francisco Bay Area."* A public meeting was held on September 1, 1998 in San Francisco, California to discuss the report and allow community members to provide comments on the report. In addition, community organizations were asked to submit written comments on the report during the Public Comment period, September 1- October 31, 1998.

The feedback received at the public meeting and during the Public Comment period has been summarized and incorporated into this addendum. The questions and comments that follow were raised at the public meeting by meeting participants. The responses were provided to the participants at the public meeting by the authors of the Northern California Cancer Center Report: "Status of Breast Cancer Research in the San Francisco Bay Area" and of the CDC Review of the Report. The questions and comments are organized into the following categories: (1) Risk Factors for Developing Breast Cancer; (2) Trends in the Incidence of Breast Cancer in the San Francisco Bay Area; (3) Trends in the Breast Cancer Mortality Rate in the San Francisco Bay Area; (4) The Status of Cancer Surveillance in the San Francisco Bay Area; and (5) The Breast Cancer Research Agenda and Recommendations. Also included are copies of correspondence related to CDC's Review of the Northern California Cancer Center Report received by CDC and CDC's written responses.

1. Risk Factors for Developing Breast Cancer

Q.1. What are the difficulties in determining risk factors for breast cancer?

A.1. Cancer of the female breast, like many forms of cancer, has a multi-factorial etiology involving both genetic and environmental/lifestyle determinants. The long latency period between exposure to causative determinants and the clinical appearance of disease makes the process of identifying specific risk factors difficult since it is necessary to analyze a lifetime of cumulative risk factors in a retrospective fashion.

- Q.2. Are there research studies comparing risk factors for breast cancer incidence among women in the United States and women in other industrialized countries to determine what factors may account for the higher incidence rate of breast cancer among women in the United States?
- A.2. There have been research proposals for such studies but, to date, funding has not been available to undertake them.
- Q.3. Is there a known link between alcohol consumption and increased breast cancer risk?
- A.3. The effect of alcohol consumption on breast cancer risk is unknown. There are studies that have shown a slight elevation, but there are others that have shown no increased risk. The mechanism by which alcohol might be involved in increasing breast cancer incidence is unknown.
- Q.4. Why is higher socioeconomic status a risk factor instead of low socioeconomic status?
- A.4. Socioeconomic status is a label for many lifestyle factors including but not limited to education, income, career path, and access to medical care. It is difficult to determine which of these combination of factors or other factors specifically impacts breast cancer risk.

Higher socioeconomic status as a risk factor could be acting as a proxy for indicators of potential environmental exposures unique to or more highly associated with higher socioeconomic groups. However, studies have suggested that potential exposures to hypothesized environmental toxins are more common in lower socioeconomic groups.

In addition to the questions posed above, the following comments were made by meeting participants regarding risk factors for breast cancer:

- CDC's review of the Status Report cites the Robbins and NCCC reports as evidence that mammography and known risk factors may explain the higher incidence of breast cancer in the San Francisco Bay Area. However, CDC also notes in its review that these studies do not address or resolve the issue of environmental risk factors. CDC cannot conclude that an increase in mammography use is the cause of an increase in breast cancer incidence without exploring the possible environmental risk factors.
- Many substances have been introduced into the environment that were thought to be safe, but are now known to be harmful, *i.e.*, lead paint, DDT, asbestos, and nicotine. CDC and other governmental organizations must halt the use of these substances until a determination can be made regarding the effect of these environmental hazards on breast cancer incidence.

- The Environmental Protection Agency (EPA) is studying thousands of chemicals in the environment to determine which ones are toxic; however, these studies only analyze high doses of these chemicals and do not address the harmful effects of exposure to low-doses of toxic chemicals.
- In March 1999, the American Cancer Society will convene a research conference on the environment and cancer to determine a direction for further research into environmental risk factors for cancer.
- A research study of environmental risk factors must include the clean-up of toxic dumps and the effect of this process on breast cancer incidence rates.
- CDC has the resources through their National Center for Environmental Health (NCEH) to study environmental risk factors. Research initiatives and funding should be concentrated in this area instead of confirming the mammography effect and other factors that have already been determined.
- This report states that early detection of breast cancer is important for long-term survival; however, many racial and ethnic minority women and other underserved women do not have adequate access to screening services. There are state and federally funded programs that provide screening to low-income women who do not have health care coverage, but these programs do not provide for treatment of the disease. The state of California has \$12 million budgeted to provide treatment services to these women, but procedures such as reconstructive surgery are not covered under this initiative, and there are disparities in the quality of care that women receive through these programs.

2. Trends in the Incidence of Breast Cancer in the San Francisco Bay Area

Q.1. What is the effect of acculturation in breast cancer incidence rates among immigrants in the San Francisco Bay Area?

A.1. Previous studies done in the United States, not specific to the San Francisco Bay Area, show that there is an effect of acculturation in increasing cancer incidence rates among immigrants. These studies have shown that the rates of various cancers in countries of origin are much lower than those of individuals who are second and third generation immigrants; as they become more acculturated in the United States their rates of various cancers approach and frequently equal those of more established populations in the United States. The incidence of other types of cancer decline in subsequent generations of immigrants to the United States.

- Q.2. Are data available to show trends in incidence rates since 1995?
- A.2. No, the data have not yet been compiled. National data for 1996 are due to be released in spring 1999.
- Q.3. Can breast cancer incidence rates be determined for the over 30 different Asian ethnic groups in the San Francisco Bay Area?
- A.3. In 1988, NCCC began collecting data on approximately 30 different Asian groups based on information contained in medical records. Many of these groups are very small in numbers making it difficult to calculate accurate rates for them. There are currently rates for Chinese, Japanese, Filipino, Vietnamese, and Korean American populations.
- Q.4. Does Marin County have the highest incidence rate for breast cancer in California?
- A.4. For the period 1988-1992, for all races combined, Marin County had the highest breast cancer incidence rate in California. During the same time period, among white women only, Marin County had the second highest breast cancer rate in California.
- Q.5. Are there any studies involving women living on military bases in the San Francisco Bay Area that investigates the relationship between not having children and the risk of breast cancer?
- A.5. One study was conducted at McClelland Air Force Base, which is outside of Sacramento, that showed no noticeable increase of breast cancer among women at that military base. Most studies of breast cancer indicate that women who never had children have a higher risk of breast cancer.
- Q.6. Is there any evidence that increased mammography causes increased reported incidence?
- A.6. The introduction or increased use of mammography in a community is thought to lead to an increased breast cancer incidence since mammography detects breast cancers that cannot be detected by clinical or self examination. The increased screening leads to an increase in the number of breast cancers that are detected over what would be expected based on breast cancer incidence prior to mammography screening. Over time, the increase in incidence levels off.
- Q.7. Did you look at incidence trends for women in the San Francisco Bay Area aged 40 years and under who do not receive widespread screening mammography?
- A.7. No. The number of women in the San Francisco Bay Area under the age of 40 who are diagnosed with breast cancer is too small to collect and analyze the cancer rates accurately. In addition, it is not possible to selectively enumerate the under age 40 population (*i.e.* denominator) which does not receive “screening mammography.”

- Q.8. Why does the San Francisco Bay Area have among the highest breast cancer incidence rates in the world?
- A.8. Since 1973 the incidence rates of invasive breast cancer (all races) in the San Francisco Bay Area have been higher than the rates of invasive breast cancer in all the National Cancer Institute's (NCI) Surveillance, Epidemiology, and End Results (SEER) program areas combined. However, the rate of newly diagnosed breast cancers in the San Francisco Bay Area peaked at 123.4 per 100,000 in 1987 and decreased 12.0 percent to 108.6 per 100,000 by 1994. Since 1991, there has been no statistically significant difference between the incidence rate in the San Francisco Bay Area when compared to the rate in all SEER areas combined, or to the rate in all other SEER areas combined (*i.e.*, excluding the San Francisco Bay Area). In general, breast cancer incidence rates in the United States are higher than in other parts of the world.
- Q.9. The report compared San Francisco Bay Area breast cancer incidence to other areas in the United States. Is it reasonable to compare rates in the San Francisco Bay Area to the aggregate United States incidence rates? Would the comparisons be more meaningful if the San Francisco Bay Area rates were compared to the rates in areas in the United States with similar demographic composition?
- A.9. The comparison of cancer incidence rates for one geographic area to incidence rates for the United States as a whole is a common public health practice. Such comparisons, especially over time, provide a "benchmark" by which state and local public health officials can monitor trends in cancer incidence to identify high rates relative to the comparison group in order to develop better local prevention and control strategies.

The comparison in the early 1980s of cancer incidence rates in the San Francisco Bay Area to the rate in all other SEER areas of the United States (combined) identified higher breast cancer rates in the San Francisco Bay Area and led to the public outcry and current intense efforts to recruit women for critical early detection services.

Additional comparisons of incidence rates for the San Francisco Bay Area to other specific geographic areas of the United States are possible. For example, NCCC reported at the public meeting that the breast cancer incidence rates in Los Angeles County were somewhat higher than those in the San Francisco Bay Area. Dr. Dee West of NCCC suggested expanding current studies to better understand the similarities and differences in breast cancer rates in the San Francisco Bay Area and Los Angeles to gain insight about their possible causes beyond known risk factors. Comparison of incidence rates in the San Francisco Bay Area to other areas of the United States with similar demographic composition is hampered by the fact that, until recently, most areas of the United States did not have population-based central cancer registries that met minimum standards of completeness, timeliness, and quality. With the advent of CDC's National Program of Cancer Registries (NPCR) in 1992, federal support for cancer registry activities is now in

place in 45 states, the District of Columbia and three territories to improve the availability of complete and accurate data for multiple uses, including geographic comparisons. To get maximum benefit from this data, CDC is seeking the authority and funding to establish a national, centralized, aggregated database that would pool incidence data from all states participating in NPCR. A centralized, aggregated database could make geographic comparisons more possible.

In addition to the questions posed above, the following comments were made regarding the report's analysis of trends in breast cancer incidence in the San Francisco Bay Area:

- The report does not distinguish clearly between incidence rates for *in situ* and invasive breast cancers. CDC shows that the incidence rate of invasive breast cancer has decreased since 1987, but does not address the reasons for high incidence rates of invasive breast cancer before the influence of mammography in the early 1980s or the increase of *in situ* breast cancer through the 1990s.

In the discussion of this comment, the authors referred to CDC's Review, pages 6-9.

- The report concludes that increased mammography contributed significantly to the increase in cancer incidence after 1978. While some of the incidence of breast cancer can be explained by increased screening, it would be helpful if additional analyses supporting this assumption were provided.

In the discussion of this comment, the authors referred to CDC's Review, page 12, Recommendation #2.

- Frustration was voiced that the report did not address the incidence of breast cancer among Hispanic women or the cultural, religious, and educational barriers to screening services for this population.

In the discussion of this comment, the authors referred to CDC's Review: page 4, paragraph 2; page 5, paragraph 3; page 10, paragraph 2; and, page 16, Exhibit 1.

- We acknowledge the difficulties with making racial/ethnic comparisons since there is no standard way that race/ethnicity is collected across states and jurisdictions. However, with the current immigration patterns and an increasing ethnically diverse country, we are challenged to address this problem and to come up with effective solutions. We believe that this area of concern should be addressed in the final report to Congress.

The Office of Management and Budget (OMB) issues policy directives for the uniform collection of race and ethnicity data by federal government agencies, including the Census Bureau. These standards are being changed to coincide with the Census in the year 2000. At that time, citizens will be able to choose multiple categories to classify themselves in regards to their race and ethnicity.

3. Trends in the Breast Cancer Mortality Rate in the San Francisco Bay Area

Q.1. Why are mortality rates higher for the following groups: African-American women in the San Francisco Bay Area, white women in San Francisco County, and Asian American/Pacific Islander women in San Mateo?

A.1. Specific data are not available from the cancer registry or the National Center for Health Statistics to answer this question. However, lack of access to mammography screening and treatment services, and other barriers to mammography utilization in these populations, such as cultural, religious, and educational factors, may be responsible for higher mortality rates.

One study in San Francisco is analyzing the system, cultural, and historical factors that may influence access to screening and treatment services for African-American women in an attempt to improve outcomes among underserved women in this group.

Q.2. What factors explain the observed racial/ethnic disparities in breast cancer survival among San Francisco women?

A.2. The NCCC Status Report noted the study “Racial/Ethnic Differences in Breast Cancer Survival Among Bay Area Women” published in the Journal of the National Cancer Institute. The results indicate that San Francisco Bay Area women diagnosed with breast cancer between 1974 and 1990 were slightly more likely to survive 5 years after diagnosis than women in other SEER areas. In addition, there were significant differences in survival from breast cancer among various racial/ethnic groups within the San Francisco Bay Area. In particular, African-American and Filipino women had poorer survival rates from breast cancer than women in other racial/ethnic groups. Some of these differences in survival may be explained by the stage of the breast cancer at diagnosis. For example, the study found that African-American women were diagnosed at a more advanced stage of the disease than women of other racial/ethnic groups. However, an analysis of racial/ethnic differences within each disease stage showed that African-American and Filipino women continued to have poorer 5-year survival rates from breast cancer than women from other racial/ethnic groups, even when all women examined were diagnosed with the same disease stage. Factors that may explain these remaining survival differences include barriers to health care access, the presence of other diseases, or biologic and genetic differences in the tumors.

- Q.3. Are there data comparing mortality rates for women who have had lumpectomies versus mastectomies at the 10-year anniversary?
- A.3. Studies at NCI are examining the efficacy of lumpectomy and post-lumpectomy radiation versus mastectomy in breast cancer survival rates on a national level. To date, these studies have shown that the two treatments have the same mortality rates for women diagnosed with early-stage tumors under 4 centimeters. No such statewide studies have been funded.

In addition to the questions posed above, the following comment was made by a meeting participant regarding breast cancer mortality rates:

- The report focuses on the value of early detection of breast cancer in improving mortality rates. However, it fails to note that mortality rates remain higher in the San Francisco Bay Area than the rest of the state.

4. The Status of Cancer Surveillance in the San Francisco Bay Area

- Q.1. What are the barriers to collecting more complete cancer registry information on treatment?
- A.1. Only data and information recorded in medical records by physicians can be used in analysis by cancer registrars. Follow-up studies to gather additional treatment information are quite costly. In addition, an increasing proportion of women are receiving treatment outside the hospital setting for which cancer reporting may be incomplete or delayed.
- Q.2. Why are patients not made more aware of the existence of cancer registries? Why not implement a system where patients are informed of the cancer registry at the time of surgery, and physicians ask for information for use in the cancer registry?
- A.2. California state legislation requires that patients be notified of the existence of the cancer registry; however, many patients are not informed and it is impossible to follow-up and interview every patient to obtain registry information. Cancer registries do attempt follow-up with some patients to determine the outcome of their treatment. At this time, patients are informed that their data will be reported to a central surveillance source. The Health Insurance Portability and Accountability Act of 1996 requires that the Secretary of the Department of Health and Human Services submit recommendations to Congress on establishing a federal standard by which all registries for public health surveillance would notify the public that confidential personal information was being collected. In addition, it promulgates the requirements for maintaining the privacy and confidentiality of this information.

Tumor registries debate how much information to collect from every patient versus more comprehensive information for use in specialized studies. The costs of expanding the databases are frequently prohibitive and it is difficult to determine the cost-effectiveness of collecting widespread data. Some health care providers attempt to collect risk-related data such as family history before screening. However, many have noted that language and literacy barriers prevent women from completing written data collection forms.

Q.3. How can response rates to participation in research studies be increased?

A.3. One of the great innovations made at the Breast Cancer Research Program for California is a mechanism called community initiated research collaboration. The concept of the program is to involve and collaborate with the community being studied in the design of research studies.

The Department of Defense has also initiated studies in which women with breast cancer are involved in all phases of the research design and study. The women participate in the peer review of research proposals, make recommendations as to which projects should receive funding, and review scientific evaluations of their health status. Collaborative efforts help to alleviate fears and barriers to participation in such studies.

Q.4. How are decisions made regarding what information to collect for use in cancer registries?

A.4. Organizational and institutional review boards and human subjects committees in hospitals, academic centers, and the federal government conduct reviews of information collected in cancer registries and make decisions to ensure that the public is protected from the risks of research. All review boards receive input from members of the community in making their decisions.

Q.5. How will local health departments be involved in the development of templates and protocols for responding to reported cancer clusters?

A.5. With the advent of CDC's NPCR, states are rapidly improving the completeness and quality of cancer data that are used as a fundamental tool in investigating cancer clusters. However, as yet, few states have adequate resources or the technical capacity to respond quickly or definitively to reports by communities of possible clusters of cancer.

Currently, responses are often not satisfactorily conclusive to either the community reporting a possible increase in cancer or to the state health department responding to the report. Rarely does a report of increased occurrence lead to new information about carcinogenic exposures or causes of cancer. Follow-up of such a report is costly and citizens may interpret the feedback of no association of the reported cancer to a clear cause or possible exposure as due to incomplete data, or to an attempt to cover-up known risks. An opportunity for cancer prevention and control through focused screening or education is often lost.

In a workshop sponsored by the Council of State and Territorial Epidemiologists in 1997, states identified critical areas of need in their health departments regarding cancer investigations. These included: additional knowledge and training, databases complimentary to the cancer registry, appropriate software applications, public and provider information about cancer clusters, model response protocols, and organizational infrastructure. No model currently exists for states to adopt or implement in responding to cancer cluster inquiries.

CDC has proposed the development of a Cancer Inquiry Response System (CIRS)--- a systematic approach to cancer surveillance that refines existing guidelines, from state and local health departments, and resources for public inquiries and cancer cluster investigations, allowing states to better respond to the information needs of the public and of policy makers about the occurrence of cancer. The goals of CIRS would be to: 1) enhance the appropriate assessment by states of public inquiries about cancer; 2) educate communities on the incidence, etiology and treatment outcome of specific cancers in response to cancer inquiries; 3) improve the process for judicious triaging of inquiries about cancer occurrence; 4) increase the technical infrastructure and the capacity of state epidemiologists or their designees and to implement CIRS in state agencies; 5) develop and test *a priori* hypotheses regarding the clustering of certain forms of cancer; and 6) test models of cancer inquiry response systems through demonstration projects in state/local health departments.

- Q.6. Data to assess breast cancer mortality rates by race and ethnicity are not available. None of the major recommendations addressed this important issue. Can you explain this?
- A.6. To calculate incidence and mortality rates, data on the number of cancer cases and deaths, as well as the total population are needed. The report discusses mortality for black and white women in the San Francisco Bay Area compared to the United States as a whole. The denominator or population data for other race/ethnicities is obtained by information collected in the United States Census and this includes very limited information on racial and ethnic groups. Statistics produced by cancer registries will only be as complete as the information contained in the Census.

The OMB issues policy directives for the uniform collection of race and ethnicity data by federal government agencies, including the Census Bureau. These standards are being changed to coincide with the Census in the year 2000. At that time, citizens will be able to choose multiple categories to classify themselves in regards to their race and ethnicity.

Q.7. The Census undercounts ethnic groups. How is this being corrected in calculating data for the San Francisco Bay Area?

A.7. CDC uses Census Bureau estimates to calculate rates. These are extrapolated yearly, but do not adjust for an undercount, as decided by the Census Bureau and the United States Congress. The U. S. Census Bureau and the Congress have decided not to adjust for undercounts. Cancer registries are attempting to improve the information about race and ethnicity, particularly for Native Americans and Alaskan Natives through the use of medical databases. CDC supports several states in the linkage of the registry database with population databases, or residence registries for some of the reservations and tribal governments in the United States, to collect an accurate account or designation for individuals who are identified in the registry with cancer. Often Native Americans in the cancer registry are reported as being white, but when registry data are linked to the populations registry for the tribal government, we find that they are Native American.

A second way to correct cancer registry data is through the expansion of data collection efforts. Two federally funded programs, NCI's SEER program and CDC's NPCR, have established cancer registries in all 50 states. By having data for every state, CDC will have larger numbers of particular ethnic groups to include in its analysis. However, Hispanics from New York City may be very different in terms of their heritage, their culture, and their patterns of immigration and acculturation than Latinos in Florida or Mexicans in Los Angeles. This is just one of the challenges we face in attempting to get better information on racial and ethnic populations.

Q.8. Why are statistics still age adjusted to 1970?

A.8. The age adjustment corrects for the aging population. Over time, incidence rates will increase because of the aging population. Age adjusting determines whether there is truly an increase in rates or if the aging population is causing rates to increase falsely. The standard population for age adjustment has changed over the decades and different agencies have used different standard populations. Secretary Shalala recently approved a proposal for federal agencies to age adjust to the year 2000 population.

Q.9. Cancer registries do not prevent breast cancer. Why do we continue to put so much of our available resources into these systems?

A.9. Cancer registration is the fundamental method in the United States by which information is systematically collected about the occurrence of cancer, the extent of disease at the time of diagnosis, the types of treatment received by cancer patients, and the outcomes of those treatments. The data from cancer registries serve as the critical foundation of all cancer control activities in the United States. Cancer registry data are used for health planning, health resource allocation, evaluation of cancer control programs, and health services research; and serve as population-based sampling frames for clinical and epidemiologic research. In addition, historically, cancer registries have played key roles in answering questions from the public about cancer. The information collected by cancer registries is useful in the development of education and prevention efforts in communities. Data are also needed to assess the impact of programs that target risk factor reduction such as changing diet and exercise habits.

In addition to the questions posed above, the following comments were made by meeting participants regarding the collection of data and the cancer surveillance system:

- It is frustrating that data for Asian American/Pacific Islander women are often aggregated since there is not a large enough sample size to accurately assess data. The lack of data on this population helps to intensify the myth that Asian American/Pacific Islander women do not get breast cancer.
- It is essential that a standardized method of collecting data on race and ethnicity be developed so that data can be compared across local, state, and regional areas.

The OMB issues policy directives for the uniform collection of race and ethnicity data by federal government agencies, including the Census Bureau. These standards are being changed to coincide with the Census in the year 2000. At that time, citizens will be able to choose multiple categories to classify themselves in regards to their race and ethnicity.

5. The Research Agenda and Recommendations

Q.1. How was the Congressional appropriation last year of \$15 million in supplemental funds to study high priority environmental issues, including breast cancer incidence, spent?

A.1. Last year Congress appropriated monies to study the relationship between environmental exposures and potential toxins to the incidence of breast cancer. The money went to NCI to study the “fingerprints” on genes of the environment.

In addition to the question posed above, the following comments were made by meeting participants regarding the nation's cancer research agenda and the recommendations put forth in this report:

- Research needs to look at the impact of acculturation on breast cancer incidence to determine factors that increase the risk among second and third generation immigrants.
- The cornerstone of cancer control efforts lies in finding and eradicating the causes of the disease. None of the studies recommended in this report address the need to examine risk factors for the disease, such as the association between higher income and education levels with an increased risk of developing breast cancer. Studies should also address the activities associated with these risk factors that increase one's likelihood of developing breast cancer.
- Only two of the studies listed in the report examine environmental risk factors and neither of these has funding to continue the study. Less than 1 percent of the funding in Northern California is addressing environmental risk factors. CDC's National Center for Chronic Disease Prevention and Health Promotion, NCEH, and the Agency for Toxic Substances and Disease Registry have been working in conjunction with the National Institute of Environmental Health Sciences and EPA to craft a research agenda that identifies the top ten questions that need to be addressed regarding the environment and cancer. There are many priorities in public health and there have not been sufficient funds to address this agenda.
- Research has shown that low-income women and women of racial and ethnic minority groups do not have equal access to screening services. The report states the importance of early detection screening in improving survival rates, yet we have not put adequate resources into programs that provide screening services to underserved women. Increasing funding and resources for these programs would increase survival rates in a large segment of the population.

Recognizing the value of screening and early detection, Congress passed the Breast and Cervical Cancer Mortality Prevention Act of 1990 to provide screening services to underserved women, including older women, women with low incomes and women of racial and ethnic minority groups. Now in its 10th year, CDC's National Breast and Cervical Cancer Early Detection Program supports screening activities in all 50 states, in 5 U. S. Territories, in the District of Columbia, and through 15 American Indian/Alaska Native organizations. By March 1998, close to 2 million screening tests for breast and cervical cancers have been provided.

- There is adequate funding for research, but the money is not being effectively spent.
- We need to remove the issues and barriers to funding and make a real commitment to finding the solution.

- CDC needs to establish a bold and in-depth research agenda that addresses and finds solutions to the breast cancer epidemic. Without an adequate agenda, collaborations will not form and solutions will not be found. This was a real opportunity to have priorities forced to the surface instead of having a passive opportunity for flotation.
- We understand that CDC did not want to make recommendations for new breast cancer research programs for which they do not have funding to conduct; however, the report would have been exceedingly valuable to community organizations had it made specific and innovative research recommendations.
- It was recommended that a task force be established to develop a clear research agenda and blueprint to find the solution. Chris Collins, representing Congresswoman Pelosi, stated that the Congresswoman would request a report by the Government Accounting Office to detail all current research topics and projects underway or planned by Federal agencies related to breast cancer and the environment.
- The San Francisco Department of Public Health is most interested in working in partnership with the local and state cancer registries to define a research agenda that will begin to bridge the current gaps in understanding the etiology of breast cancer and improving outcomes among women with breast cancer.

**Section 4: Written Correspondence Related to CDC's Review
of the Northern California Cancer Center (NCCC) Status Report**

- Enclosure 1: Inquiry from Mitchell H. Katz, M.D., Director of Health, City and County of San Francisco
- Enclosure 2: Response from Louise Galaska, M.P.A., then Acting Director Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion to Mitchell H. Katz, M.D.
- Enclosure 3: Inquiry from Wendel Brunner, Ph.D., M.D., M.P.H., Director of Public Health, Contra Costa Public Health
- Enclosure 4: Response from Louise Galaska, M.P.A., then Acting Director Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion to Wendel Brunner, Ph.D., M.D., M.P.H.
- Enclosure 5: Inquiry from Bradley Angel, Executive Director, Greenaction
- Enclosure 6: Response from Louise Galaska, M.P.A., then Acting Director Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion to Bradley Angel
- Enclosure 7: Inquiry from Andrea Martin, Founder and Executive Director, The Breast Cancer Fund
- Enclosure 8: Response from Louise Galaska, M.P.A., Deputy Director Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion to Andrea Martin
- Enclosure 9: Response from Andrea Martin, Founder and Executive Director, The Breast Cancer Fund

City and County of San Francisco

Department of Public Health



Mitchell H. Katz, MD
Director of Health

October 28, 1998

James Marks, MD, MPH
 Director, National Center for Chronic Disease Prevention
 & Health Promotion Division of Cancer Prevention & Control
 Centers for Disease Control & Prevention
 Mail Stop K-40
 4770 Buford Highway, NE
 Atlanta, Georgia 30341-3724

Subject: Report to Congress: CDC Review of the Northern California Cancer Center
 Report: Status of Breast Cancer Research in the San Francisco Bay Area

Dear Dr. Marks:

I am writing to provide feedback on the report, CDC Review of the Northern California Cancer Center Report: Status of Breast Cancer Research in the San Francisco Bay Area released August, 1998. We appreciate the efforts of the Centers for Disease Control and Prevention (CDC) in preparing this report. The forum in which the results were presented and discussed was timely as the San Francisco community has already engaged these issues in several locally organized forums, in particular the Breast Cancer Summit, organized by Mayor Willie Brown in 1997.

Reflecting the reality of breast cancer research, the draft report raises more questions than it answers. We would like to provide feedback on the report. Several questions have been raised by many San Franciscans, both community residents and breast cancer activists. First, why does the San Francisco Bay Area have among the highest breast cancer incidence rates in the world? And second, what factors explain the observed racial/ethnic disparities in breast cancer survival among San Francisco women?


The report compared Bay Area breast cancer incidence to other areas in the United States. Is it reasonable to compare rates in the Bay Area to the aggregate United States incidence rates? Would the comparisons be more meaningful if the Bay Area rates were compared to the rates in areas in the United States with similar demographic composition? We acknowledge the difficulties with making racial/ethnic comparisons since there is no standard way that race/ethnicity is collected across states and jurisdictions. However, with the current immigration patterns and an increasing ethnically diverse country, we are challenged to address this problem and to come up with effective solutions. We believe that this area of concern should be addressed in the final report to Congress.

Also, the report concludes that increased mammography contributed significantly to the increase in cancer incidence after 1978. While some of the incidence of breast cancer can be explained by increased screening, it would be helpful if additional analyses supporting this assumption were provided.

The San Francisco Department of Public Health is most interested in working in partnership with the local and state cancer registries to define a research agenda that will begin to bridge the current gaps in understanding the etiology of breast cancer and improving outcomes among women with breast cancer.

Thank you again for initiating this important report, and for sharing the results through the recent forum.

Sincerely,


MITCHELL H. KATZ, MD
Director of Health



Centers for Disease Control
and Prevention (CDC)
Atlanta GA 30341-3724

January 15, 1999

Mitchell H. Katz, M.D.
Director of Health
City and County of San Francisco
101 Grove Street
San Francisco, California 94102

Dear Dr. Katz:

Thank you for your letter providing feedback on the Centers for Disease Control and Prevention (CDC) *Review of the Northern California Cancer Center Report: Status of Breast Cancer Research in the San Francisco Bay Area*.

The Northern California Cancer Center (NCCC) reported, and CDC confirmed, that breast cancer incidence rates in the San Francisco Bay Area have decreased 12.0 percent since 1987. Since 1991, there has been no statistically significant difference between the incidence rate in the San Francisco Bay Area compared to the rate in all other areas of the United States (combined) that participate in the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program. Unfortunately, the United States has the highest breast cancer rates in the world, the reasons for which are under intense investigation by multiple Federal agencies and academic, medical institutions.

The NCCC reported that there were significant differences in survival from breast cancer among various racial/ethnic groups in the San Francisco Bay Area. Based on review of cancer incidence data, NCCC reported that some of the differences in survival may be explained by the stage of the breast cancer at diagnosis. For example, NCCC reported that African-American women were diagnosed at a more advanced stage of disease than women of other racial/ethnic groups. However, an analysis of racial/ethnic differences within stage showed that African-American and Filipino women continued to have poorer five-year survival from breast cancer than women from other racial/ethnic groups, even when all women studied were diagnosed with the same stage of disease. NCCC suggested that the remaining survival differences could be a result of barriers to health care access, the presence of other diseases, or biologic and genetic differences in the tumors.

Comparison of incidence rates for one geographic area to incidence rates for the United States as a whole is a common public health practice. Such comparisons, especially over time, provide a "benchmark" by which state and local public health officials can monitor trends in cancer incidence to identify high rates relative to the comparison group in order to develop better local prevention and control strategies.

The comparison in the early 1980s of the incidence rates in the San Francisco Bay Area to the rate in all other SEER areas of the United States (combined) identified the higher breast cancer rates in the Bay Area and led to the public outcry and current intense efforts to recruit women for critical early detection services.

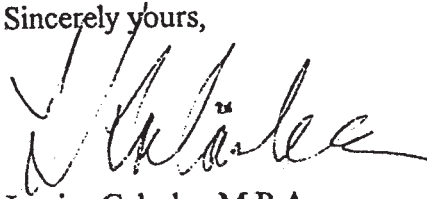
Additional comparisons of incidence rates for the Bay Area to other specific geographic areas of the United States are possible. For example, NCCC reported at the public meeting that the breast cancer incidence rates in Los Angeles County were somewhat higher than those in the San Francisco Bay Area. Dr. Dee West of NCCC suggested expanding current studies to better understand the similarities and differences in breast cancer rates in the Bay Area and Los Angeles to gain insight about their possible causes beyond known risk factors. Comparison of incidence rates in the Bay Area to other areas of the United States with similar demographic composition is hampered by the fact that, until recently, most areas of the United States did not have population-based central cancer registries that met minimum standards of completeness, timeliness, and quality. With the advent of CDC's National Program of Cancer Registries (NPCR) in 1992, federal support for cancer registry activities are now in place in 45 states, the District of Columbia and three territories to improve the availability of complete and accurate data for multiple uses, including geographic comparisons. To get maximum benefit from this data, CDC is seeking authority and funding to establish a national, centralized, aggregated database that would pool incidence data from all states participating in NPCR. A centralized, aggregated database could make geographic comparisons similar to those you propose more possible.

The NCCC and CDC review of the breast cancer incidence and mammography utilization data for the Bay Area suggested that the higher rates in breast cancer were due, in part, to the higher use of mammography--the greater the number of women screened, the greater the number of breast cancers detected. Higher prevalence of known breast cancer risk factors in the Bay Area may have also contributed to the elevated rates. CDC's report recommended that data should be analyzed on the prevalence of mammography utilization since 1991 and trends in the prevalence of known breast cancer risk factors in the San Francisco Bay Area to assist in the interpretation of time trend data for breast cancer incidence and mortality. I understand that state and local public health officials have already embarked on additional analyses related to these issues. Dr. William Wright, California Department of Health Services, will have the most recent information on such data. He may be contacted at (916) 322-5863. For additional information on breast cancer trends in the Bay Area, please contact Dr. Dee West, (510) 429-2500, or Dr. Wright. Thank you for providing feedback on CDC's review of the NCCC Report.

Page 3 - Mitchell H. Katz, M.D.

An addendum to the review addressing the questions and concerns expressed by the community about breast cancer in the San Francisco Bay Area is being prepared.

Sincerely yours,

A handwritten signature in black ink, appearing to read "Louise Galaska". The signature is fluid and cursive, with a small "TM" trademark symbol above the "a" in "Galaska".

Louise Galaska, M.P.A.
Acting Director
Division of Cancer Prevention and Control
National Center for Chronic Disease
Prevention and Health Promotion

cc:
Kathleen Carey

WILLIAM B. WALKER, M. D.
HEALTH SERVICES DIRECTOR
WENDEL BRUNNER, M.D.
PUBLIC HEALTH DIRECTOR



CONTRA COSTA
HEALTH SERVICES

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November 12, 1998

Claire V. Broome, M.D., Acting Director
Centers for Disease Control and Prevention
National Center for Chronic Disease Prevention and Health Promotion
Division of Cancer Prevention & Control
M.S. K-64
4770 Buford Highway N.E.
Atlanta, GA 30341-3717

**RE: REPORT TO CONGRESS: CDC REVIEW OF THE NORTHERN CALIFORNIA
CANCER CENTER REPORT "STATUS OF BREAST CANCER RESEARCH IN THE
SAN FRANCISCO BAY AREA"**

Dear Dr. Broom:

I am writing to express my disappointment in the CDC report to Congress on breast cancer in the Bay Area. We local public health officials look to the Centers for Disease Control and Prevention for professional expertise and leadership to address the public health issues that confront our communities. Your agency's response to the Bay Area's concerns about breast cancer is inadequate in both those areas.

I won't comment here specifically on the technical problems with the CDC report and analysis. Those problems have been outlined in some detail in a letter to you from the Breast Cancer Fund, to which I am a signator. I am more concerned here about the CDC's core public health responsibilities, particularly the responsibility to provide careful assessment and thoughtful policy recommendations, which would provide direction to the Bay Area and the nation on breast cancer.

The following is an article I prepared on the CDC Bay Area breast cancer report for the newsletter of one of the Bay Area breast cancer groups our health department has been working with over the last two years. It is written for a lay audience, but I hope it conveys to you the concerns I have about the CDC role in breast cancer in the Bay Area:



Don't Worry, Be Happy; the CDC on Breast Cancer in the Bay Area

On September 1st the Centers for Disease Control and Prevention arrived in San Francisco from Atlanta and released their long awaited report on breast cancer in the Bay Area. Local media picked up the CDC press release and announced "Good News for Women — about Breast Cancer." The report revealed that 12 new cases and three deaths from breast cancer occur every day in the Bay Area, and the breast cancer rate appears to be stabilizing at 25% above the level in the '70's. If this is good news, one can only be relieved that it doesn't contain what the CDC considers bad news, or wonder how they would describe, say, an Ebola outbreak in Manhattan.

Public concern about breast cancer is well justified. The United States has the highest breast cancer rate identified anywhere in the world; 50% higher than most European countries, and 5 times the rate of breast cancer in Japan. White Americans have two times the rate of breast cancer of Asian Americans, while the rate for Hispanics and African Americans falls in between. There are no known effective prevention strategies for breast cancer, and a genuine cure remains elusive. Nonetheless, early detection with screening mammography and proper medical treatment greatly increases a woman's chance for living out her life free from a recurrence of the disease. Unfortunately, not everyone in America has the same access to health care; African American women die at the highest rate from breast cancer, despite their lower incidence.

In 1994 the Northern California Cancer Center released a thoughtful and disturbing study that showed the Bay Area had the highest rate of breast cancer identified anywhere on the planet. That designation is largely symbolic; the rest of the Nation has high rates as well. Nonetheless, the report galvanized local breast cancer survivors and public health officials to demand a search for the cause.

Finding the cause is difficult. Contra Costa County has the second highest rate of breast cancer in the Bay Area, and the largest concentration of refineries, petrochemical industry, and hazardous waste in the State. To some breast cancer activists, the association appeared obvious. But to many public health professionals, the factors involved seemed much more complicated. Marin County, for instance, has the Bay Area's highest rate of breast cancer, yet it is as unpolluted a populated area as you can find in the country.

In 1996, the Breast Cancer Fund brought together activists, public health officials, and scientists to outline a research agenda. The Bay Area, with its extensive Tumor Registry, diverse ethnic communities, recent immigrants, and determined activists could be a laboratory to study why the United States has such high rates of disease. Local Congresswomen gave the CDC a mandate to review the breast cancer situation in the Bay Area and make recommendations.

Incredibly, the CDC acted as if its main mission was to pacify women, rather than find the cause of their disease. The CDC reassured us that breast cancer is on the wane in the Bay Area, and that the apparent high rate was just an artifact of screening mammography (or maybe it was due to life-style factors, you get to take your choice). Since the Bay Area, by their new calculations, no longer has the highest rate, nothing particular needs to be done here. The fact the national breast cancer rates have rising alarmingly over the last two decades was wholly ignored.

To support these conclusions, the CDC was highly selective in how they analyzed their data. The report shows that the age adjusted invasive breast cancer rate in the United States was relatively constant from 1973 to 1982, shot up 25% from 1982 to 1987, and has since then held steady. The Bay Area rates mirror the national trends, although they are generally somewhat higher. The CDC explanation for this 25% rise is the widespread introduction of screening mammography in the early '80's.

Screening does lead to earlier diagnosis, and doubtless caused the rate of breast cancer to climb more steeply in the '80's (the so-called "harvest effect"), but screening cannot account for our higher rate of invasive cancer in the Bay Area and the country in the '90's. In fact, screening should lower the reported invasive cancer rates. Mammography detects cancer at an earlier stage; that is how it saves lives. The CDC study shows a fourfold increase in *in situ* breast cancer, an early stage detected by mammography and not included in the invasive statistics. Had those cancers remained undetected, as most were in the '70's, many would have spread, and even further raised our invasive cancer rates.

The CDC seemed almost desperate to show a San Francisco area rate lower than the national average, even if ever so slightly. To do that they ignored the ethnic composition of the populations and compared the Bay Area average of all ethnic groups with the rest of the nation as a whole. Of course the Bay Area is an ethnically diverse region with a much higher population of Asians, especially recent Asian immigrants with their low breast cancer rates. If the ethnic composition of the Bay Area were taken into account, the Bay Area would have almost certainly still shown a higher rate of breast cancer than the rest of the country. The CDC epidemiologists, however, didn't do that basic analysis.

Why did the CDC go to such great efforts to downplay the significance of breast cancer in the Bay Area? It appears they were obsessed by the possibility they would be asked by community activists and politicians to do an extensive epidemiology study focusing on an environmental cause for a "breast cancer epidemic" in the Bay Area. Many public health professionals (including myself) believe such an effort could be misdirected and unproductive. However, instead of responding as national public health officials, explaining their concerns to the activists and proposing a clear, scientifically sound and broad based research agenda, the CDC hid behind an essentially patronizing and disingenuous report and hoped the problem would go away.

Unfortunately, the problem of breast cancer in the Bay Area and the nation isn't going away-- it may even be getting worse. Women and men concerned about breast cancer have shown great commitment to knowing the causes and seeing a cure. The nation's leading public health officials should do the same.

Sincerely,



Wendel Brunner, Ph.D., M.D., M.P.H.
Director of Public Health

WB:ah

Enclosure

cc: Daniel Miller, M.D., M.P.H.
Association of Bay Area Health Officials
Congresswoman Ellen Tauscher
Congressman George Miller



Centers for Disease Control
and Prevention (CDC)
Atlanta GA 30341-3724

January 15, 1999

Wendel Brunner, Ph.D, M.D., M.P.H.
Director of Public Health
Contra Costa Public Health
597 Center Avenue, Suite 200
Martinez, California 94559

Dear Dr. Brunner:

Thank you for your letter, expressing your concerns about the Centers for Disease Control and Prevention (CDC) Review of the Northern California Cancer Center (NCCC) Report: Status of Breast Cancer Research in the San Francisco Bay Area, and for the article that you prepared for the newsletter of one of the Bay Area breast cancer groups. I have been asked to respond on behalf of Dr. Claire Broom. We received, under separate cover, the letter that you referenced from the Breast Cancer Fund outlining a technical review of the CDC and NCCC Reports. We will be responding directly to the Breast Cancer Fund's letter and will provide a copy to you at that time.

We will include your letter as part of the public comment in response to CDC's Review and the NCCC Report. Thank you for your thoughtful comments.

Sincerely,

A handwritten signature in cursive script, appearing to read "Louise Galaska".

Louise Galaska, M.P.A.
Acting Director
Division of Cancer Prevention and Control
National Center for Chronic Disease
Prevention and Health Promotion

cc:
Kathleen Carey
NCCDPHP/OD



November 5, 1998

Claire V. Broome, MD
 Centers for Disease Control and Prevention
 National Center for Chronic Disease Prevention and Health Promotion
 Division of Cancer Prevention and Control
 Mail Stop K-64
 4770 Buford Hwy NE
 Atlanta, GA 30341-3717

Subject: Report to Congress: CDC Review of the Northern California Cancer Report
 Status of Breast Cancer Research in the Bay Area

Dear Dr. Broome,

Greenaction works on a daily basis with communities in the San Francisco Bay Area and across the Southwestern United States impacted by toxic pollution. We see first hand the impacts from toxic exposure on public health in these communities, often including high rates of breast cancer.

Greenaction endorses the comments to you recently submitted by the Breast Cancer Fund regarding the status of Breast Cancer Research in the Bay Area. We join them in calling on your agency to increase research efforts regarding potential environmental causes of breast cancer.

The alarming rates of breast cancer in the Bay Area and the unacceptable toll on women, their families and friends calls for thorough research and action for prevention to address the breast cancer epidemic. Breast cancer rates remain high in the Bay Area, and it is little consolation that the Bay Area rates may be similar to other areas. The fact remains that there is too much breast cancer here in the Bay Area, and too many carcinogenic chemicals continue to be emitted into our environment. This reality must be further researched and addressed.

Sincerely,

Bradley Angel
 Bradley Angel
 Executive Director



915 Cole Street, Box 249, San Francisco, CA 94117
 Tel: 415-588-3475 Fax: 415-588-5079 www.greenaction.org

Printed on 100% recycled, unbleached paper using soy-based ink





Centers for Disease Control
and Prevention (CDC)
Atlanta GA 30333

March 3, 1999

Mr. Bradley Angel
Executive Director
Greenaction
915 Cole Street, Box 249
San Francisco, California 94117

Dear Mr. Angel:

This is in response to your letter to Dr. Claire Broom regarding breast cancer rates in the San Francisco Bay Area. We appreciate your concern and interest in seeking increased funding for research efforts regarding potential environmental causes of breast cancer. Breast cancer is the most common nondermatologic cancer among American women and the second only to lung cancer as the cause of cancer related deaths. An estimated, 178, 700 new cases of breast cancer among women will be diagnosed and 43, 500 women are expected to die of the disease in 1998.

The Centers for Disease Control and Prevention (CDC) and the Northern California Cancer Center (NCCC) recently released the results of a review of breast cancer incidence and mortality for the San Francisco Bay Area compared to the United States as a whole. During a public meeting in San Francisco on September 1, 1998, during which CDC and NCCC reports were released, numerous members of the community and of breast cancer advocacy groups similarly expressed their frustrations and desires to have better information about potential causes of breast cancer.

One of the findings in CDC's review of the NCCC report was that there were nearly 40 research studies covering a broad spectrum of topics and approaches currently underway in the San Francisco Bay Area to better understand the occurrence of cancer, including several studies related to potential environmental causes of breast cancer. The CDC Review recommended that, due to the multi-factorial nature of the potential causes of breast cancer, broad-based approaches to breast cancer research in the San Francisco Bay Area and in the United States as a whole should be continued.

The NCCC presented in its report, and in the public meeting, several new directions for research related to breast cancer in the Bay Area. CDC's review suggested that the new directions for research proposed by NCCC were worthy of consideration after appropriate peer review of research proposals and protocols.

A number of factors frequently categorized as environmental exposures have been proposed as possible causes of increased risk for breast cancer. These factors include: ionizing radiation; organochlorines such as dichloro-diphenyl-trichloro ethane (DDT), 1,1-dichloro-2,2-bis ethylene (DDE), polychlorinated biphenyls (PCBs) electromagnetic fields; polycyclic aromatic hydrocarbons (PAHs); lack of solar radiation excessive exposure to light; and hair dyes. Only ionizing radiation is generally considered an established risk factor. The other factors have inconclusive evidence from studies completed so far.

The CDC has active research programs related to potential environmental causes of breast cancer including studies of: breast cancer among women exposed to polybrominated biphenyls; environmental risk factors in breast cancer among women in Maryland; predictive value for breast cancer of serum organochlorine levels; meta-analysis of the association between hormone replacement therapy and risk for breast cancer; breast cancer among Native Alaskan women exposed to organochlorines; a case control study of breast cancer among Asian American women; levels of selected xenoestrogens and breast cancer; and analyses of serum pesticides and polychlorinated biphenyls for a study of breast cancer.

These studies are being conducted by CDC's National Center for Environmental Health. Additional investigations are underway in the Agency for Toxic Substances and Disease Registry focusing specifically on the health effects of documented toxic exposures.

We appreciate your support for research efforts regarding potential environmental causes of breast cancer. We look forward to continuing dialogue with our public and private partners related to cancer and the environment. Again, thank you for your letter of concern. It will be incorporated in a summary of public comment about CDC's Review of Breast Cancer in the San Francisco Bay Area.

Sincerely,



Louise Galaska, M.P.A.

Acting Director

Division of Cancer Prevention and Control

National Center for Chronic Disease

Prevention and Health Promotion

October 28, 1998



Claire V. Broome, MD
Centers for Disease Control and Prevention
National Center for Chronic Disease Prevention and Health Promotion
Division of Cancer Prevention and Control
Mail Stop K-64
4770 Buford Hwy NE
Atlanta GA 30341-3717

Subject: Report to Congress: CDC Review of the Northern California Cancer Report - Status of Breast Cancer Research in the Bay Area

Dear Dr. Broome:

I am writing on behalf of The Breast Cancer Fund (TBCF) and the other organizations undersigned to comment and provide perspective on the abovementioned draft report on breast cancer in the Bay Area.

The Breast Cancer Fund (TBCF) is a non-profit organization founded in 1992 to create funding and awareness for innovative breast cancer research, education and patient support. TBCF collaborates with organizations across the country to develop and support programs. Our mission is to eliminate deaths from breast cancer in our lifetimes and support the healing of body, mind and spirit of women with the disease.

First, we want to acknowledge the effort that the Centers for Disease Control and Prevention (CDC) has invested in preparing this report. We particularly appreciate the public presentation that CDC arranged here in San Francisco, which afforded the opportunity for community leaders to raise their concerns directly with CDC leaders and scientists. While our perspectives and approaches differ, we believe the best results will come from our combined efforts, and hope you will address the many issues raised at the public forum.

Second, this letter summarizes our comments on both the approach to the report and the findings it presents. We appreciate the opportunity to review the draft and hope that our comments will be reflected in the final product. Ultimately, we would like to see CDC institutionalize a closer working relationship with the breast cancer advocacy community.

As you know, TBCF is deeply concerned about the long-term increase in breast cancer incidence in the Bay Area, the United States, and other parts of the world. Incidence has risen approximately 1% per year since the mid-1940s. As your report notes, breast cancer is second only to lung cancer as a cause of deaths from cancer among women. More than 40,000 U.S. women will die of breast cancer this year. Breast cancer is the most common cancer among women and accounts for one third of new cancer cases in women in North America and Northern

Enclosure (7) Page 1 of 8

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October 28, 1998

Page 2

Europe. During the 1990s, approximately two million women in the U.S. will be diagnosed with breast cancer and nearly half a million will die from the disease.

TBCF has explored the question of why breast cancer incidence in the Bay Area was reported to be the highest in the world in the 1992 report from the International Agency for Research on Cancer. Having the world's highest rate of any disease would be of concern. However, our most important goal is to find out why incidence rates remain high and appear to be continuing to rise in the Bay Area and elsewhere. We hope that CDC will assist TBCF and other organizations and individuals interested in women's health to find and eliminate the causes of breast cancer.

The report you presented was mandated by the House Appropriations Committee as follows:

"Collaborate with state and local health departments to review existing cancer registry data on breast cancer incidence and mortality in the San Francisco Bay Area to determine what area-based assessments may be necessary and, on the basis of this review, to issue a report on the findings and recommendations."

The charge to CDC was to examine breast cancer incidence and mortality in the Bay Area and to address two issues. The first was whether area-based assessments may be necessary. The second was to prepare a report with findings and recommendations related to the need for further research. Unfortunately, CDC has completed neither of these tasks.

The draft report discusses data on breast cancer incidence in the Bay Area and concludes that additional research is not needed. We believe that the analysis presented in the report fails to support this conclusion, for reasons detailed later in this letter. In addition, findings and recommendations in the report are very narrowly focused and do not represent the type of leadership or direction that we expect from CDC, our principal public health agency, given the grave hazard that breast cancer represents to women.

We believe the report needs to consider why breast cancer is so common the Bay Area, rather than simply analyzing reasons for relatively small differences in incidence rates between the Bay Area and other areas under surveillance in the US. This would address the more fundamental public health issue and lead to recommendations that might better reflect the full scope of the problem.

We request that CDC outline a research agenda to answer the critical question of why incidence rates remain so high. Although risk factors for breast cancer have been identified, they "explain" at most 50 percent of cases in the Bay Area and elsewhere. Clearly, research on new explanations is essential. "Explaining" only half the breast cancer cases is simply not enough. Moreover, the report does not explain the varying results for different ethnic groups, another area worthy of careful review and additional research.

October 28, 1998

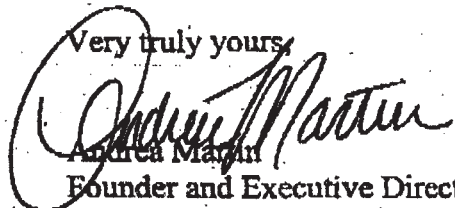
Page 3

The report overstates the scope of research now underway. The CDC finding that 40 research studies are being conducted in the Bay Area reflects outdated information, as several of these studies have no current funding. In particular, TBCF believes that more research on potential environmental causes of breast cancer is needed. The CDC report dismisses this hypothesis as unworthy of further effort with little analysis.

TBCF believes that a long term prospective study of women, beginning at the time of conception, may be needed to adequately ascertain the causes of breast cancer. The magnitude of the problem and the terrible burden that breast cancer imposes on women, their families and friends, warrant no less of a response.

Although TBCF prepared the response to the CDC report, we have circulated this letter and the comments that follow to a number of interested groups and agencies. The organizations listed below cover a broad spectrum of groups concerned with the high incidence of breast cancer in our community. They have reviewed the TBCF response and support both the concepts in this letter and the detailed critique that follows.

Very truly yours,



Andrea Martin
Founder and Executive Director

Rachel Morello Frosch, President
Breast Cancer Action
San Francisco, California

Lisa Bailey, MD, Past President
California Division, American Cancer Society*
Oakland, California

Judith Jones, Executive Director
Community Breast Health Project
Palo Alto, California

Wendel Brunner, MD, PhD, Director
Contra Costa Health Services Department
Martinez, California

*organization listed for identification only

October 28, 1998

Page 4

Amy Kyle, PhD, MPH
Consulting Scientist
San Francisco, California

Mary Gould
Marin Breast Cancer Watch
Ross, California

Gina Solomon, MD, Senior Scientist
Natural Resources Defense Council
San Francisco, California

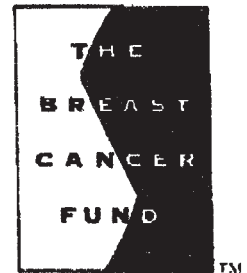
Marion Moses, MD, Executive Director
Pesticide Education Center
San Francisco, California

Margaret Taylor, Director
San Mateo County Health Services Agency
San Mateo, California

Diane Estrin, Executive Director
Women's Cancer Resource Center
Berkeley, California

cc: w/attachment

Congresswoman Nancy Pelosi
Senator Dianne Feinstein
Senator Barbara Boxer
Donna Shalala, Secretary of Health & Human Services
Governor Pete Wilson
Lieutenant Governor Gray Davis
Jeffrey P. Koplan, Director, Centers for Disease Control and Prevention
Administrator, Agency for Toxic Substances and Disease Registry
Kim Belshe, Director California Department of Health Services
Dee West, Director, Northern California Cancer Center



The Breast Cancer Fund Analysis and Comments

REPORT TO CONGRESS

CDC Review of the Northern California Cancer Center Report: Status of Breast Cancer Research in the San Francisco Bay Area

Findings and Recommendations

The first finding of the report concludes that incidence of invasive breast cancer in the Bay Area has decreased since 1987 and is now comparable to that for other areas of the country. While Bay Area incidence rates may be decreasing and may not be higher than elsewhere in the US (based on the limited data available), incidence rates throughout the US are unacceptably high. This should be reflected as a policy concern for CDC, as it poses a major public health issue. The finding makes it sound as if the high rate of breast cancer is acceptable and fails to address the major concerns of The Breast Cancer Fund and of women. In particular, CDC should include a research agenda to determine why incidence rates remain so high and what public health interventions would reduce it. CDC needs a "bigger picture" perspective as a leading public health agency. Moreover, as noted later, CDC presents no statistical analysis to support its conclusion that rates are declining.

With regard to research, Finding 5 says that 40 research studies covering a broad spectrum of topics and approaches are underway in the Bay Area. This appears to be based on outdated information. Several of the studies included on a list provided by CDC no longer have funding.

Recommendation 3 says that broad-based approaches to breast cancer research in the Bay Area and the US should be continued. The Breast Cancer Fund believes that sufficient "broad-based" research to address the "unexplained" causes of breast cancer is not yet underway. The CDC should expand this recommendation to encompass a research agenda to address unexplained causes of breast cancer. This will require considering innovative approaches and theories. None are apparent in this draft.

Background

It would be useful to note the limitations of the concept of "risk factors" in describing causes of disease. It is widely recognized that at least some of the "risk factors" for breast cancer, such as higher socio-economic status and residence in northern cities, are proxies for something else. It

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may also be true that some of the risk factors actually reflect increased vulnerability to other causes of cancer rather than causes in themselves. If this proves to be true, then identifying both underlying causes and vulnerability status would be important to understanding patterns in the disease. At the very least, a clear discussion about risk factors and what they do and do not tell us about causes of disease is important.

The discussion of the potential role of environmental factors in breast cancer at page 2 is cursory at best. Citing one reference not exactly on point is an insufficient basis to reach a conclusion about the important issue of whether environmental exposures may contribute to breast cancer. The conclusion appears to represent a pre-existing opinion of the authors, rather than the result of a credible review. Either a reasonable attempt should be made to examine this issue fairly, or the conclusion should be omitted from the report.

The report states that early detection and treatment of breast cancer are a key to control of the disease. Again, a clear conceptualization of what risk factors represent is critically important. If some risk factors increase vulnerability to exposure to other agents, then control of the other agents would prevent cancer, irrespective of our ability to modify the factors that increase vulnerability. In any case, the Breast Cancer Fund does not believe that it is acceptable to women to address breast cancer by early detection and treatment. We must re-focus our efforts on finding causes and looking for prevention strategies and not accept the status quo.

Methods

There appear to be a number of important methodological problems with the analysis.

The fact that classification of ethnic status for California and for SEER is different poses problems for making comparisons by ethnic groups. Yet, this issue is clearly very important. The Breast Cancer Fund believes that the responsible agencies should solve this problem, to allow for more complete comparisons. The current situation is a disservice to the public. Both incidence and mortality rates differ substantially among ethnic groups. If comparisons cannot be made for specific ethnic groups between California and national data, then it is difficult to see how CDC can conclude that there are no current differences in incidence rates between the Bay Area and elsewhere. At page 5, the report notes that the most accurate comparisons are by ethnic group. If the CDC cannot accurately compare findings by ethnic group between the Bay Area and other areas, it would be wise for the CDC to clearly state the limitations of its conclusion that there are no important differences in incidence rates.

It is significant that the CDC did not describe its statistical method for assessing trends in yearly incidence for the Bay Area. It appears that no statistical method was used. Again, this calls the conclusions into question. We would expect to see some "bumps" in the curve from year to year.

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It would be important to use proper methods to determine whether trends are statistically significant.

Detailed findings

Finding 1. The incidence of invasive breast cancer in the San Francisco Bay Area has decreased since 1987 and now is comparable to the rate in the other areas of the United States, combined, participating the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program.

CDC concludes that rates have decreased in the Bay Area since 1987. It would be useful for the CDC to provide a statistical analysis of the time trend here.

Finding 2. Analysis of breast cancer incidence in the San Francisco Bay Area in the mid-1980s compared with other areas of the United States suggests that the higher rates were due, in part, to the higher use of mammography, i.e., the greater number of women screened, the greater number of breast cancers detected. Higher prevalence of known breast cancer risk factors in the Bay area may have also contributed to the elevated rates.

The CDC concludes that increased mammography contributed significantly to the increase in cancer incidence after 1978. However, the report does not present any analysis or information to support this. The CDC should substantiate this theory, especially since it dismisses other theories about causes of breast cancer and causes of increased incidence of breast cancer that it considers to be unsubstantiated.

The CDC report appropriately explains some of the limitations of the Robbins and NCCC studies cited in this section. However, these limitations do not seem to be reflected in the conclusions that are drawn.

Finding 3. Recent cancer surveillance data indicate that the incidence of invasive breast cancer is decreasing in the San Francisco Bay Area. The decrease may be due to several factors or a combination of factors including a mammography screening effect, less complete cancer reporting from outpatient medical facilities, or changes in the demographic profile of the population.

The CDC should explain why the incidence rates reported for DCIS and invasive breast cancer are diverging. If the CDC concludes that a leveling off in incidence rates of breast cancer are due to reaching an equilibrium after a screening effect, why would the same pattern not be shown in incidence rates for DCIS?

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Finding 4. Death rates for breast cancer in the San Francisco Bay Area have decreased since 1991 and are now comparable to the US rates.

The Breast Cancer Fund is concerned about differential health outcomes including mortality. The report says that African-American women have higher mortality for same-stage cancer than other women in the Bay Area do. The CDC should explore why this may be the case.

The report concludes that mortality rates are higher for Asian, non-Hispanic women in San Mateo County and for white non-Hispanic women in San Francisco County than for women in these groups in California as a whole. This is an important conclusion that should be reflected in the findings summarized at the outset. It would appear to be at odds with the assurances in the rest of the report that the pattern of breast cancer in the Bay Area is the same as elsewhere.

Finding 5. Nearly 40 research studies covering a broad spectrum of topics and approaches are under way in the San Francisco Bay Area to better understand the occurrence of breast cancer.

As noted above, the information cited in this finding appears to be out-of-date and misleading. This should be corrected.

Finding 6. Cancer surveillance in the San Francisco Bay Area has included very complete case identification and high quality case information.

It would be useful for the CDC to assess the budget available to the cancer registries in the State of California with regard to whether it is sufficient to carry out both existing responsibilities and to address the issues raised by the increasing number of cases being treated outside hospitals. The cancer registries are obviously critical to a good surveillance program. However, their budgets have been reduced in recent years. The CDC, having identified the importance of surveillance, should review funding. Also, CDC should provide a more informative analysis of the adequacy of the national surveillance system to allow for useful comparisons.



Centers for Disease Control
and Prevention (CDC)
Atlanta GA 30341-3724

March 29, 1999

Ms. Andrea Martin
The Breast Cancer Fund
282 2nd Avenue
San Francisco, California 94105-3130

Dear Ms. Martin:

This is in response to your letter regarding the "Centers for Disease Control and Prevention's (CDC) Review of the Northern California Cancer Center Report (NCCC): Status of Breast Cancer Research in the San Francisco Bay Area." I have been asked to respond on behalf of Dr. Claire Broom. Let me begin by thanking you for your contribution and that of The Breast Cancer Fund in helping to organize the public meeting held in San Francisco on September 1, 1998. In addition, I appreciate you taking the extra time to provide written commentary and feedback regarding CDC's Review and the NCCC's Report. You discuss several aspects of the Report, including issues related to surveillance, risk factors (including environmental exposure to carcinogens), and research. I have attempted to respond to some of your major concerns below.

As you know, in September 1997 the House Appropriations Committee of the United States Congress urged the CDC and the Agency for Toxic Substances Disease Registry (ATSDR) to "collaborate with state and local health departments to review existing cancer registry data on breast cancer incidence and mortality in the San Francisco Bay Area to determine what area-based assessments may be necessary and, on the basis of this review, to issue a report on findings and recommendations." CDC met this charge and issued the final report at a public meeting in September 1998.

The CDC Review reports that breast cancer is the most common non-dermatologic cancer among American women and the second only to lung cancer as the cause of cancer-related deaths. Breast cancer incidence rates in the United States are higher than in other parts of the world. The incidence of invasive breast cancer in the San Francisco Bay Area has decreased since 1987 and is now comparable to the rate in other areas of the United States, combined, that participate in the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program. However, this disease remains a critical health problem for the Bay Area and for the nation, and is a priority for CDC.

In your letter you state that CDC's Review "concludes that additional research is not needed". On the contrary, the recommendations in CDC's Report to Congress focus primarily on areas where additional investigation and inquiry are needed. Recommendation #3 of the Report states that "Due to the multi-factorial nature of the potential causes of breast cancer, broad-based approaches to breast cancer research in the San Francisco Bay Area and in the United States as a whole should be continued. The new directions for research on breast cancer in the Bay Area proposed by NCCC in the Status Report are worthy of consideration through appropriate peer review of full proposals and protocols.

The CDC, as the nation's prevention agency, acknowledges the critical importance of the primarily prevention of breast cancer - there is much we need to learn about the causes of breast cancer and how to prevent this disease. CDC's National Center for Environmental Health has an active research agenda related to breast cancer and the environment including studies of: breast cancer among women exposed to polybrominated biphenyls; environmental risk factors in breast cancer among women in Maryland; predictive value for breast cancer of serum organochlorine levels; meta-analysis of the association between hormone replacement therapy and risk for breast cancer; breast cancer among Native Alaskan Women exposed to organochlorines; a case control study of breast cancer among Asian American women; levels of selected xenoestrogens and breast cancer; and, analyses of serum pesticides and polychlorinated biphenyls for a study of breast cancer.

However, research regarding the association of many behavioral factors or environmental exposures with breast cancer has not consistently demonstrated increased risk for the disease, and many established risk factors for breast cancer are not amenable to prevention. Therefore, current breast cancer control efforts must include multiple strategies and approaches. For example, early detection through mammography could reduce mortality by 17 - 30 percent in women over age 40 when coupled with appropriate treatment. Until better information is available about the causes of breast cancer, we cannot retreat from our commitment to fully utilize the tools we have available right now to save women's lives. With this goal in mind, CDC also implements the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), providing resources to states for comprehensive breast cancer control activities such as public education, medical provider education, early detection through mammography and clinical breast exam, diagnostic follow-up and case management services. Since its inception, the NBCCEDP has provided over 1 million screening mammograms to uninsured and underserved women in the United States, with particular emphasis on members of minority groups.

In your letter, you ask why the incidence rates reported for ductal carcinoma in situ (DCIS) and invasive breast cancer are diverging. The CDC Review states that analysis of breast cancer incidence in the San Francisco Bay Area in the mid-1980s, compared with other areas of the United States, suggests that the higher rates of breast cancer were due, in part, to the higher use of mammography, i.e., the greater number of women screened, the greater number of breast cancers detected. Higher prevalence of known breast cancer risk factors in the Bay Area may have also contributed to the elevated rates.

The Report further states that initial increases in the incidence of breast cancer result from dissemination of screening technology (mammography) into the community, resulting in the diagnosis of previously undetected, prevalent, and smaller tumors that would have otherwise been detected symptomatically in later years. NCCC's Status Report presents the results of several analyses and studies in support of this hypothesis. CDC's Review critiques the methods and conclusions of those analyses and details the studies' limitations. DCIS is detectable only through mammography. An objective of the early detection of breast cancer is to find higher proportions of the cancers in preinvasive stages (when it is more curable) and lower proportions in later stages. Divergence of the DCIS (increasing) and invasive (decreasing) incidence curves is exactly what we would hope to find in effective early detection programs. Unfortunately, the diffusion of mammography to all segments of our society has not occurred equally. A significant proportion of women in the U.S. still have never had a mammogram nor have had a recent mammogram. The efficacy of mammography as an early detection strategy to reduce mortality from breast cancer is dependent on women getting mammograms on a regular basis.

Your letter also expressed concerns about the difference in breast cancer mortality rates among different racial and ethnic groups. CDC's Review reported the observation that death rates for breast cancer among white women in the Bay Area have started to decline and approach the rate for white women in the United States as a whole. Data for black women in the Bay Area fluctuated because of the statistically small numbers but appear to follow a trend similar to that of black women in the United States as a whole. Breast cancer mortality rates for black women in the United States have not shown a sustained decline. Some differences in survival may be explained by the stage of breast cancer at diagnosis, barriers to health care access, the presence of other diseases, or biologic and genetic differences in the tumor.

Your letter expressed concerns about the way risk factors for breast cancer were addressed in the Report. A comprehensive, exhaustive recounting of the scientific literature on the possible and confirmed etiologies of breast cancer was not within the scope of this report. The assessment in CDC's Review that only ionizing radiation is generally considered an established risk factor from among the hypothesized environmental exposures is the result of long term knowledge and review of the scientific literature to date. CDC's Review also notes that higher socioeconomic status as a risk factor theoretically could be acting as a proxy for potential environmental exposures unique to or more highly associated with higher socioeconomic groups.

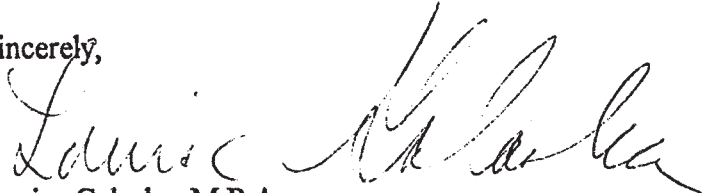
You suggested that CDC evaluate the need for adequate funding and resources for cancer surveillance and specifically for the California cancer registry. CDC's Review addresses one aspect of the limitations of the national surveillance efforts by proposing the development of the Cancer Inquiry Response System. Details are provided in the Review on pages 11-12. In addition, I am enclosing a copy of a manuscript published since the release of CDC's Review that describes national cancer surveillance efforts. Through the National Program of Cancer Registries, CDC supplements State funds to support state cancer registries - including California's - to improve the timeliness, quality and comprehensiveness of cancer incidence data. With \$24 million in FY 1999 appropriations, CDC also provides resources to stimulate utilization of the data for

Page 4 - Ms. Martin

health planning, evaluation and research. CDC's long-term goal to provide leadership to states in developing comprehensive cancer surveillance programs which will identify trends and disparities in cancer burden by race, ethnicity and geographic area and serve as a critical component in developing, implementing and evaluating efforts to reduce the burden of cancer in states will require additional resources.

A copy of your letter to Dr. Broome, and this response, will be included in the addendum to the Review, which will be distributed in future with all copies of the Review that CDC disseminates. Please accept my personal thanks for your help in organizing and presenting the public meeting in September.

Sincerely,

A handwritten signature in cursive script, appearing to read "Louise Galaska".

Louise Galaska, M.P.A.

Deputy Director

Division of Cancer Prevention and Control

National Center for Chronic Disease

Prevention and Health Promotion

cc:

Kathleen Carey
NCCDPHP/OD

April 27, 1999

Louise Galaska, M.P.A., Deputy Director
Division of Cancer Prevention and Control
National Center for Chronic Disease Prevention and Health Promotion
Centers for Disease Control and Prevention
Atlanta, GA 30341-3724



Dear Ms. Galaska:

Thank you for your detailed response (4/6/99) to our October 1998 letter regarding the REPORT TO CONGRESS *CDC Review of the Northern California Cancer Center Report: Status of Breast Cancer Research in the San Francisco Bay Area*. Unfortunately, most of your discussion merely re-states items that we already found to be inadequate in the report. Our specific comments follow and are noted according to paragraph ¶, and page in your letter.

¶ 1, p.2:

Your letter cites Recommendation #3 in the CDC report as a response to our comment that the report concludes "that additional research is not needed". As you note the Report suggests that the present approaches to research should be continued. Therein lies the problem. We state that new and innovative approaches are required such as long-term prospective studies.

¶ 3, p.2:

Our letter never suggested a retreat from the use of current tools to save women's lives. However, we did request new research that would attempt to understand the relationship between environmental factors and breast cancer. Again, the only pathway for that reality is long-term prospective studies that examine exposures at critical times: in-utero, pre-adolescent, pregnancy, and menopause.

¶ 4, p.2:

You misinterpret our concern about the increase in DCIS. The NCCC separates the issues of DCIS and invasive breast cancer and then proceeds to conclude that the rates of breast cancer incidence have leveled when in fact that is true for invasive but not for DCIS. Comparison from the mid-1980's until now continues to show an increase which cannot be rationalized according to the mammography effect alone. Until we have a reliable way of predicting whether a particular DCIS will become invasive, it is illogical and misleading not to address the growing numbers of DCIS incidents. Again, the NCCC/CDC-report avoids that important issue.

¶ 2, p.3:

Although you address some of the mortality issues with regard to race and ethnicity, you again fail to respond to our issues concerning incidence. Since the Bay Area has large numbers of women of color with lower incidence rates, comparisons of incidence need to be made between white women only in all the SEER areas. Inclusion of other ethnic groups gives the predicted lowered incidence for the Bay Area and provides a false reading of an actual situation.

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The Breast Cancer Fund never expected a complete review of the entire literature concerning risk factors. However, we do expect an acknowledgement of several studies that indicate that the traditional risk factors alone cannot explain the geographic variations. [See Madigan MP et al, *JNCI* 1995;87(22):1681-5 and more recently Laden F, Hunter DJ et al, *JNCI* 1997; 89(18):1373-8.] Without commenting about such work the impression is given that NCCC/CDC is prepared to negate the possible contribution of environmental factors.

Again, The Breast Cancer Fund appreciates your recent letter. However, as we indicate in this response, a number of our issues remain unaddressed. Therefore, we request that this letter follow your letter of 4/6/99 in the addendum to the Review of the CDC Report.

Sincerely,



Andrea R. Martin, Executive Director
The Breast Cancer Fund

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