Recommendations for the Federal Government

- Increase federal funding through the National Institutes of Health (NIH) to promote greater research into the prevention of breast cancer.
- Increase funding for research into the causes of disparities in breast cancer incidence and outcomes among the different ethnic groups. Increased research must address the economic, social and cultural factors that interfere with access to modern, curative therapies, delivered in a timely fashion so as to maximize their benefit. Particular attention should be paid to the higher risk and mortality in younger African-American women.
- Increase funding aimed at eliminating barriers to screening for breast cancer for all women, especially those groups with the lower utilization of these services and more adverse outcomes after treatment. Hispanic women in our study reported more barriers to access for screening and had lower rates of mammography.
- Recommend that women at high risk consider screening before age 40. African-Americans, Ashkenazi Jews, and women with a strong family history of breast cancer are at potentially higher risk and may warrant earlier screening than the general population. These screenings should remain available and insurable.



- Provide guidance to state and local governments to assist them in the publication and distribution of informational materials so that women can better understand that the majority of breast cancer cases occur among women who have no family history of breast cancer. All women need to understand the importance of yearly screening mammograms beginning at age 40, as well as other measures important in limiting risk. Information should highlight differences among ethnic groups with regard to breast cancer risk. Women surveyed uniformly overestimated the role of family history and genetics in breast cancer, which may adversely affect many women's screening behavior. EHHI's study showed that if women where made aware that over 80% of all breast cancers occur in women with no family history, they would be more vigilant about mammographic screening.
- Expand the effort to identify or exclude causal roles for a variety of environmental contaminants in breast cancer. Increased effort should be directed to assessing exposures that occur both during the prenatal period, as well as in early childhood and adolescent years, in relationship to breast cancer risk.

Recommendations for State Governments

- States should provide information about known risk factors for breast cancer to allow women to assess their own relative risks. Materials should describe prevention strategies and how to access screening opportunities within the state.
- States should establish and regularly update a website that provides information about the known and suspected risk factors for breast cancer. The website should include:



- The number of women diagnosed with the disease, both nationally and within each state, updated on an annual basis. Data should include ethnic differences within those statistics;
- How women can reduce their risk factors for breast cancer within their control;
- How and where women can access screening opportunities within each state.
- States should provide *free* or *limited-cost* (by sliding scale) counseling and breast cancer screening services targeted to minorities and the uninsured. These services should be available at convenient locations and times to ensure accessibility for women facing economic and social barriers. Innovative efforts to partner with not-for profit organizations, corporate and local businesses, as well as the medical community, should be encouraged to widen access to these services.
- States should undertake a broad public health campaign targeted to enhancing women's understanding of breast cancer risks to increase women's utilization of screening tests. Women in this survey uniformly overestimated the role of family history and genetics in breast cancer. This overestimation may adversely affect many women's screening behavior. When women were made aware that more than 80% of all breast cancers occur in women without a family history, they reported that they would be more vigilant about mammographic screening. States should use the media to publicize this fact, along with other breast cancer prevention strategies. EHHI's study showed that the majority of women surveyed said they obtained their information about breast cancer from media sources.

Recommendations for Foundations

- Both increased funding and education are needed to address the disparities in both breast cancer incidence and mortality in the minority community, particularly among young African-American women.
- Women uniformly overestimate the role of family history and genetics in breast cancer, which may adversely affect many women's screening behavior. EHHI's study shows that women would be more vigilant about getting mammographic screening if they were aware that more than 80% of all breast cancers occur in women without a family history of the disease. This fact needs to be publicized.
- Assist in the dissemination of information about breast cancer to women at high risk for the disease, including African American women, Ashkenazi Jews, and those with a strong family history of the disease. Women in high-risk groups need to be better informed of their risk of early-onset breast cancer so they can consider screening before age 40. Mammographic screenings should remain available and insurable for these vulnerable groups.
- Increase funding for research into effective treatments for breast cancer in all women, paying particular attention to African-American women and other at-risk minority populations.
- There is a growing need for research and education efforts devoted to lifestyle factors that may contribute to adverse breast cancer outcomes. The growing obesity epidemic in early childhood, adolescence, and young adulthood is a critical influence in breast cancer development and outcome, and should be a priority for research and intervention. Partnerships among organizations can broaden these efforts and serve as models for the governmental, corporate and the not-for-profit community.
- The majority of women get their breast cancer information from the media. Given the many areas of misunderstanding about breast cancer among the surveyed women, there is a great need for wider dissemination of accurate information through media sources. Foundations can be helpful in supporting these educational efforts.
- Access to breast cancer screening should be improved. Women would also benefit from better education about the critical need for timely screenings and the importance of yearly follow-up exams for all women, irrespective of level of risk, beginning at age 40. Foundations, in cooperation with the medical community, can offer significant support for these activities.

Recommendations

for the Medical Community: Institutions, Physicians and Healthcare Providers



- Healthcare providers and institutions must focus their educational efforts on emphasizing the importance of screening for all women, paying particular attention to vulnerable populations.
- Healthcare institutions should educate primary care providers, including internists, family practitioners, gynecologists, and physicians in training—as well as nurses working with minority populations—about the higher incidence of breast cancer among younger African-American women who have a higher risk of more aggressive cancers. The critical need for patient follow-up, appropriate screenings, and lifestyle interventions cannot be overemphasized.
- Institutions should maximize continuity of care for women who lack a single primary care provider. Fragmentation of care for minority women remains a significant barrier that reduces the likelihood of timely and appropriate care.
- To limit barriers to screening and treatment, institutions should strongly consider the use of patient "navigators" who can facilitate timely follow-up studies and care involving multiple practitioners and services.
- African-American women should be educated about their higher risk for early-onset breast cancer and the critical importance of early detection through mammographic screening. Educational efforts could be facilitated by African-American groups, including the National Medical Association (NMA) and the NAACP, as well as local community and church-affiliated organizations. The goal should be to encourage understanding of breast cancer risk factors and the benefits of early detection in improving cancer survival. Medical institutions should partner with community organizations in these efforts.
- Assure the timely start of adjuvant therapy for early-stage breast cancer, including chemotherapy in the most effective dose and schedule; hormonal treatments when appropriate; and localized breast irradiation in the appropriate setting. Healthcare providers and institutions should make every effort to educate minority populations, in particular, about treatment benefits, while limiting barriers (social, economic, educational or geographic) that may impair full and timely compliance with these important therapies.

- Women should be apprised of the potential benefits of breast-feeding and, whenever possible, be encouraged to breast-feed for at least six months, in line with the American Academy of Pediatrics recommendations. African-American women, who are at higher risk for premenopausal breast cancer, but whose breast-feeding rates are lower, should be made aware of the the protective effects of breast-feeding.
- Institutions should recognize the barriers to care represented by the costs incurred by low-income women for screening, transportation and childcare needs, as well as the out-of-pocket expenses for treatment. This is particularly problematic for women requiring on-going chemotherapy and radiation with multiple visits to a variety of service providers.
- Additional resources and education should be devoted to systems that facilitate rapid and complete follow-up after abnormal tests and studies.
- Minority women are more likely to receive care that does not reflect standards of the 2000 National Comprehensive Cancer Network. All institutions should strive to provide care in accordance with evidence-based guidelines for all patients diagnosed with breast cancer.



- Increased research should be devoted to the role of genetic risk factors in breast cancer within the minority community.
- Institutions and practitioners must be knowledgeable about modifiable breast cancer risk factors, including obesity, inactivity, alcohol consumption and hormone replacement therapy, in order to counsel patients about healthy lifestyles. Physicians need to be aware of the role of excessive weight in adverse outcomes. Most research indicates that physician recommendations about diet, exercise and weight control are important in ensuring compliance.
- Multiple programs have been instituted to provide financial assistance to low-income women, such as the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), the Breast and Cervical Cancer Prevention Act of 2000, and the Avon Foundation's AVONCares. These and similar programs should be accessed wherever possible to help disadvantaged populations.

Recommendations for Individuals

- Women should follow recommended guidelines for mammographic screening, including follow-up studies on a regular basis. This is particularly important for African-American women who are, according to our survey, largely unaware of their higher risk for early-onset breast cancer. Mammographic screening at a younger age should be considered for this group.
- In addition to African-American women, others at high risk, such as those with a strong family history and those with the BRCA-1 or BRCA-2 gene, should consider obtaining a screening mammogram before age 40. They should also consider MRI screening at appropriate intervals based on their physician's recommendations.



- Women should avoid weight gain in early adulthood by eating a healthy diet, rich in vegetables and fruit, low in saturated fat, with a moderate intake of monounsaturated fat (olive and canola oils), along with regular exercise and physical activity. Avoiding weight gain is crucial for all women, but is of particular concern for African-American women, in whom increased body weight may contribute to their adverse breast cancer outcomes.
- Beginning in childhood, parents should foster a healthy diet and include regular exercise for their children. Avoidance of obesity and providing physical activity is critical.
- Women should avoid the use of long-term HRT, particularly combinations of estrogen and progestins.
- Women at higher risk for breast cancer should limit alcohol intake to one to two drinks per week. If women consume alcohol on a regular basis, they should consider taking a daily multivitamin containing folic acid.
- Women at high risk should exercise at least four to five times a week.

Women at significantly higher risk, such as those with a family history or prior benign breast disease, should discuss with their physicians the option of preventive medications,

such as tamoxifen, or other hormonal treatments. In many cases, the benefit of these agents may significantly exceed their risk. Because EHHI's survey showed that most women are unfamiliar with this option, greater effort should be made to explain the potential benefits of Selective Estrogen Receptor Modulator (SERMs). Recent data support the use of the alternative SERM agent raloxifene (Evista), which provides benefits similar to tamoxifen in reducing breast cancer risk,



while also improving bone density. Raloxifene has been shown to cause fewer adverse effects, including an absence of increased endometrial cancer risk, lower risks of blood clots and strokes, and lower rates of cataract formation. Because of its improved risk profile, many women may find raloxifene a more acceptable alternative to tamoxifen.

Because we do not know the exact interplay between environmental contaminants and breast cancer, women should avoid exposures to carcinogens and endocrine disrupters. Exposures to pesticides and other chemicals should be avoided, especially during vulnerable periods of growth, such as pregnancy, early childhood and adolescence. Until there is more data about the role that chemical exposures play in breast cancer incidence, reducing pesticide and chemical exposures will remain the most prudent course of action.