

ZBC Newsletter Spring 2009

Breast Cancer Forum for Younger Women Offers Information and Strategies for Prevention

By Suzan Berns

When young women develop breast cancer, it's usually more aggressive and more difficult to identify. While the incidence rates of breast cancer in women under the age of 40 is low compared to older women, the prognosis and survival rates are likely to be worse and hence awareness of risk and access to preventive care is essential.

These points were emphasized among the topics presented, along with diagnostic technologies, hereditary risks, screening guidelines and prevention measures and lifestyle changes, at the groundbreaking *Breast Cancer Prevention Community Education Forum for Younger Women* on Saturday, Feb. 7, 2009 at Carr Auditorium at San Francisco General Hospital. Zero Breast Cancer sponsored the forum in partnership with the UCSF/SFGH Avon Comprehensive Breast Care Program.

Some 130 people including college students and other young women, breast cancer advocates and clinicians in the field attended the day-long event which was funded by the Avon Foundation and the Marin County Board of Supervisors. The event was the first of its kind directed specifically to women under 40 who comprise just a small percentage of women who develop the disease earlier in life.

Janelle Wang, co-host of ABC-7 TV's *The View From the Bay* and an advocate in the fight against breast cancer emceed the day. Medical experts from University of California San Francisco (UCSF) and San Francisco General Hospital (SFGH), plus other professionals who deal with women's health and breast cancer issues addressed the audience. California Assemblywoman Fiona Ma made a brief appearance to comment on her work to pass AB1108, legislation banning *phthalates* in children's toys and childcare products. Ms. Ma encouraged audience members to become politically involved and take action to ensure that preventative health legislation is passed.

Zero Breast Cancer Executive Director Janice Barlow welcomed participants to the forum and pointed out that because breast cancer is considered a disease of aging, it is not often a topic of discussion among young adults. While incidence is low, Ms. Barlow said, survival rates of those diagnosed when they are younger than age 40 is also lower.

In her presentation titled "Environmental and Lifestyle Strategies for Breast Cancer Risk Reduction," Barlow noted that researchers used to look at either genetic or environmental influences to determine the cause of breast cancer. The new model, Barlow said, is to look at them together, along with ancestry. Multiple gene-environment interactions may ultimately affect breast cancer risk and outcomes. Social justice issues in communities that have a disproportionate number of toxic waste sites are now factored into breast cancer research with diverse racial and ethnic populations. Culture, where you live when the disease is diagnosed, where your mother lived when she was pregnant with you, what

you eat, and your socio-economic status may all contribute to your lifetime susceptibility for developing breast cancer.

A number of lifestyle choices can reduce some of these risks. Barlow suggested keeping track of exposure to radiation; limiting alcohol consumption and eating folate-rich foods such as green leafy vegetables (that also may modify the effects of alcohol consumption); avoiding second-hand smoke which has chemicals that settle in the breast tissues; avoiding altogether or limiting hormone replacement therapy where possible; breastfeeding infants for up to a year; maintaining body leanness; and engaging in moderate exercise at least three to four hours a week.

“The weight of evidence is pretty strong that these strategies have the potential to reduce your risk for breast cancer,” Barlow said,

“We all know we’re special in California,” quipped Judith Luce, MD, in the forum’s medical overview, alluding to widely published statistics indicating the state has the highest rate of cancer in the nation. Even so, studies from 1988 to 2002 reflect a decrease in mortality rates for all women with breast cancer, yet incidence remains steady for young women diagnosed with the disease.

In California, some 5.5% of all women with breast cancer are under 40 and 4% of all breast cancer deaths occur in women under 40, Luce said. “That’s a small percentage, but a large number of women.”

Dr. Luce, a Clinical Professor of Medicine at UCSF and Director of Oncology Services at SFGH, noted that practitioners have gained some information on the occurrence of breast cancer in women under 40. They have learned that:

- Inheritance of the BRCA1 and 2 gene mutation is responsible for about one-quarter of the cases;
- Hormones, usually in the form of *older* high dose contraceptives, increase the risk by 20 to 25 percent;
- Exercise both reduces the risk of developing breast cancer and results in better outcome for pre-menopausal women who do have the disease;
- Beginning menstruation at a younger age increases risk and having babies before age 30 and breastfeeding decreases it;
- Education and income are factors associated with developing and surviving breast cancer.

Luce told the audience that there are some breast signs that need not be a source of excessive worry, but should be reported to a health provider: These include nipple discharge, which she said is most often normal; breast pain; and lumps that come and go. It’s when the lumps stay that you need to be concerned, she said.

In her presentation on “Medical Prevention Treatments and Younger Women,” Luce noted that lumpectomy and mastectomy had a similar survival rate to each other. In many cases, she suggested, chemotherapy is more effective for younger women than older women. Younger women have a greater chance of recurrence of breast cancer or long-term complications such as heart disease or leukemia from the treatment compared to older women. This is because younger women have many more years of risk ahead of them. For this reason, she said, about half of

young women with breast cancer opt for a mastectomy. Studies show that most women who decide to have a mastectomy are happy with the decision.

Dr. Luce encouraged women considering chemotherapy for breast cancer who still wish to have children to discuss options for preservation of fertility before beginning treatment, including egg harvest for in vitro fertilization. Chemotherapy may induce menopause or shorten the reproductive lifespan, but it will not cause birth defects, she said.

To counter bone loss resulting from early menopause, Luce said to begin a regimen of calcium, vitamin D and weight bearing exercise. Chemoprevention with tamoxifen, though not widely used, has been found to work in staving off recurrence. In addition, tamoxifen protects bone density, but all women should take measures to prevent pregnancy while using tamoxifen. No other drug prevention has proven useful, including soy and omega-3 fatty acids, which have potential hazards and no proven benefits, she stated.

In her talk on “Imaging Young High Risk Women: the Pros, the Cons, the Options”, Lori Strachowski, MD, Associate Clinical Professor, UCSF, stated that when it comes to screening for breast cancer, mammography remains the “gold standard.” While current protocols suggest that mammography screening should not begin until a woman is 40 years old, there are exceptions for screening younger women who have a family history of breast cancer, who carry the BRCA gene mutation, or who have had prior radiation exposure. While the age of 40 is relatively arbitrary, this recommendation is based on multiple factors including the risk of breast cancer, higher breast density in younger women making cancers harder to find, and greater susceptibility of young breasts to the potential negative effects of radiation.

According to Dr. Strachowski, who serves as Medical Director of the Avon Comprehensive Breast Care Center at San Francisco General Hospital, overall, approximately 85% of breast cancers are detected on mammography. However, in women with extremely dense breast tissue, this number may decrease to only 30% to 40%. Digital mammography, a relatively new technology which performs slightly better in women who are pre-menopausal, under the age of 50, and have dense breasts, is therefore preferred in this select group of women when it is an available option.

Two additional techniques, ultrasound and breast MRI (Magnetic Resonance Imaging) which use sound and magnetic waves respectively, also play a role in breast imaging, said Strachowski. These techniques are typically used as problem-solving tools; however, they may be used in conjunction with mammography for screening some young, high-risk women. Some of the advantages of these techniques include no radiation, no compression and fewer limitations due to breast density. While the addition of these techniques may find more cancers, more benign growths will be found as well, leading to unnecessary worry, needless biopsies and additional costs which account for some of the reasons they are not recommended for screening in the general population.

Strachowski stated that various professional organizations support slightly different recommendations, though most agree upon yearly mammography beginning at age 40 for average risk women in the general population. For higher risk women, yearly screening mammography may begin 10 years before the age a first degree relative was diagnosed

with pre-menopausal breast cancer; however, not before age 30. For very high risk women who carry the BRCA1 or BRCA2 gene mutation, yearly screening may begin between ages 20 - 25 and 25-30 respectively with both mammography and MRI, alternating between the two techniques every six months. Noting that recommendations are general guidelines, Strachowski stressed the importance of women consulting with their physicians and genetics risk counselors to determine what is in their personal best interests.

In order for women to be better informed and have more control over their breast health, Strachowski explained that federal regulations dictate that all women receive a letter explaining the results of their screening mammogram in “laymen’s” terms. In addition, if a woman desires a second opinion or to transfer her care to another facility, she is also entitled to one free copy of her mammography images.

The Clinical Breast Exam (CBE) is the most common method of detection for breast cancer for women under age 40. After age 40 it is used in conjunction with mammograms. For this reason, said Nancy Dunn, MS, RNC, it is essential that this technique be done in an organized and thorough manner.

According to Ms. Dunn, President-Consultant, PRO-Health Inc. in Salem, Oregon, most breast lumps are found by fingers. Proper palpation can detect breast cancers as small as three millimeters, or about one-eighth inch in diameter, in their earliest stages. The discovery of a lump by CBE before a mammogram can direct a technician to produce more useful images.

Dunn described the High Quality Clinical Breast Exam, a standardized technique she and others are teaching clinicians to ensure breasts are properly examined.

“It’s not just what’s in your bra,” she said. In the High Quality CBE, the clinician palpates a pentagon-shaped area between the collar bone, breast bone and two fingers below where your bra ends, in vertical strips, she explained. The recipient should be lying on her side with her arm up, in a “Cleopatra” position to flatten breast tissue on the chest wall. Each breast should be examined for a minimum of three minutes.

Dunn suggests that women begin getting clinical breast exams at age 20 and schedule them annually or at least every three years. The best times are between day five and 10 of the menstrual cycle.

While most breast cancer is sporadic, about 5% to 10% is hereditary and another 15% to 20% results from a combination of family genes and environment, said Robin Lee, MS, CGC, a genetic counselor at UCSF/SFGH Cancer Risk Program. Hereditary breast cancer is caused in large part from the passing down, from either the maternal or paternal sides, of mutated BRCA1 and BRCA2 genes. These specific mutations are found in one in 800 in the general population, but in families with Ashkenazi Jewish heritage the incidence is one in 40. Although these mutations are rare, women who carry them have a

greatly increased risk for developing breast and ovarian cancer over their lifetime, compared with women who do not carry the genetic mutation.

For individuals who carry a hereditary mutation, there is a 50% chance that they will pass the gene down to their offspring and a 50% chance that they will *not* pass the gene down. Genetic testing for mutations in the BRCA1 and BRCA2 genes are available to high risk families, Ms. Lee noted in her presentation “Genetic Counseling and Testing for Hereditary Breast Cancer.”

Lee believes there are real benefits of testing to high-risk women. “If we identify the gene, we can direct you to proper care. If you didn’t inherit it, that’s a huge, huge piece of information.” There is federal legislation that prohibits insurance companies from considering genetic information in determining coverage. In fact, many insurance companies will cover the testing if it is medically indicated, said Lee.

In high risk women, lifestyle changes, such as those noted earlier, may decrease their risk by 20%, said Mary Beattie, MD, MAS, Associate Professor of Medicine, Epidemiology and Biostatistics at UCSF and Director of Clinical Research, UCSF Cancer Risk Program, UCSF Women’s Health. A low fat diet, though not statistically significant, “probably won’t hurt,” Beattie commented.

Some women choose risk-reducing surgery including salpingo-oophrectomy (removal of the ovaries and fallopian tubes) or mastectomies with reconstructive surgery. The latter is 95% effective in preventing breast cancer, Dr. Beattie reported in her presentation “Breast Cancer Prevention for Women at High Genetic Risk.”

A panel of women’s health program leaders noted the importance of having insurance and offered pointers for accessing health insurance coverage and/or public health programs for breast cancer screening services in the Bay Area. Panelists included Laura Kleinman, MSW, Community Health Resource Center; Diane Carr, RN, NP, Director, Breast and Cervical Cancer Services, San Francisco Department of Health; Rina Bello, Gabriella Patser Program: Breast Cancer Connections; and Barbara Clifford, RN, CNM, MPH, Program Manager of the California Cancer Detection Program *Every Woman Counts*.

Speaking on behalf of the AVON Comprehensive Breast Care Program at San Francisco General Hospital, Shermineh Jafarieh, MS, presented an overview of this community and hospital-based program that provides clinical breast evaluation and treatment services paired with culturally-sensitive outreach and navigation services to women who receive care at SFGH. The SFGH Avon program also partners with UCSF research groups to conduct studies to improve access and quality of breast care to the medically underserved. Following the forum, several attendees joined Drs. Strachowski and Luce for tours of the SFGH Avon Comprehensive Breast Care Center.

Thirty-five community and healthcare organizations that work on behalf of women currently or potentially affected by breast cancer partnered with the co-sponsors to

promote this forum. Representatives from these agencies will reach communities in nine Bay Area counties as well as statewide breast care programs. Individual participants committed to take action and share the information learned with their family and friends.