



SOCIETY FOR
WOMEN'S HEALTH RESEARCH

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NATIONAL SURVEY REVEALS GAP IN RISK COMMUNICATION BETWEEN BREAST CANCER SURVIVORS AND HEALTH CARE PROFESSIONALS

- *Approximately 42 percent of women who completed adjuvant (post-surgery) treatment and 50 percent of those still receiving adjuvant treatment did not know that more than half of breast cancer recurrences occur five or more years after surgery*
- *Experts issue nationwide call to action urging breast cancer survivors and health care professionals to openly discuss ongoing risk of recurrence*

New York, NY, May 4, 2005 – Survivors of early breast cancer want information about their risk of recurrence, but nearly half are not aware of statistics surrounding ongoing breast cancer risk, according to a new survey conducted by the Society for Women's Health Research (the Society). The survey, conducted by Roper Organization/NOP World, was unveiled during the Town Hall meeting attended yesterday by leaders in the breast cancer community. The participants concluded that communication between patients and health care professionals must be enhanced.

The survey included 300 women who were either currently receiving, or had completed five years of adjuvant (post-surgery) treatment for early breast cancer with hormonal treatment, such as tamoxifen. The results showed that 67 percent of those who had completed adjuvant treatment without experiencing a recurrence believed they were “cured.” But in reality, data show that approximately one-third of women with hormone-dependent early breast cancer will eventually experience a recurrence, and half of those recurrences will occur beyond five years following surgery.

According to the Town Hall meeting participants, this misperception may, in part, be caused by a breakdown in effective communication between patients and health care professionals. A woman's risk of breast cancer recurrence is calculated on a personal level, yet nearly one-quarter of women with early breast cancer who had completed adjuvant treatment, and 40 percent of women still receiving treatment, said they had never discussed their risk of recurrence following completion of adjuvant treatment with their health care professional. However, 95 percent of all women surveyed said they want to learn everything they can about preventing recurrence.

The Roper survey is part of *Life After early Breast Cancer: Improving Your Chance of Staying Cancer Free (Life ABC)*, an educational campaign initiated by the Society and supported by

Novartis Oncology. *Life ABC* is designed to raise awareness of the risk of recurrence for women with early breast cancer and encourage an ongoing dialogue about this risk between these women and their health care professionals.

“The survey suggests that women want information about their risk of recurrence, but many of them have not yet discussed this with their health care professionals, and nearly half of those surveyed say that much of the information available through other sources is confusing,” said Phyllis Greenberger, president and chief executive officer of the Society for Women’s Health Research. “Through *Life ABC*, we will celebrate survival with the goal of improving communication between patients and their health care professionals, so both groups can make informed decisions that can significantly improve the chance of staying cancer free.”

Life ABC Impact Report Reveals Need for Clearer Communication

The basis for the *Life ABC* program is a compelling new report, *Science, Perceptions and Communication Surrounding Risk of Recurrence*, which reviews the latest research examining the risk of breast cancer recurrence and health care professional and patient communication about that risk, and was the basis of the Town Hall meeting. The Society enlisted a panel of leading breast cancer advocates and cancer information specialists to review and contribute to the report. In addition, expert contributors include Andrea Gurmankin, Ph.D., assistant professor, Harvard School of Public Health and the Dana-Farber Cancer Institute; Linda Vahdat, M.D., director of the Breast Cancer Research Program and associate professor, Weill Medical College of Cornell University; and Ursula Matulonis, M.D., director of Medical Gynecologic Oncology, Dana-Farber Cancer Institute and assistant professor, Harvard Medical School.

Life ABC focuses on ongoing communication between patients and health care professionals, about such issues as the importance of proper diet and exercise, as well as regular follow-up examinations. A summary of the report and a tip sheet to help patients navigate a conversation about risk of recurrence with their health care professionals are available on the Society’s Web site, <http://www.womenshealthresearch.org>.

“It is very important for breast cancer survivors to understand their own personal risk for recurrence, and to weigh that risk when making decisions about lifestyle as well as treatment,” said Dr. Gurmankin. “It is up to health care professionals to help patients understand their risk by reassuring those who are overestimating their chance of recurrence, and informing those who underestimate their risk of the need for prevention and of the many steps they can take to increase their chances of remaining cancer free.”

Many factors play a role in breast cancer recurrence; therefore, the risk is different for every woman. Following health care professional recommendations for self-examinations and regular follow-up visits with a health care professional are important components of ongoing care for breast cancer patients. Maintaining a healthy diet and exercising regularly have been shown to help. Women should also discuss with their health care professionals treatment options and lifestyle modifications to help improve their chance of staying cancer free.

The term “early breast cancer” refers to breast cancer in stages 0, I and II at the time of diagnosis. In stage 0, the cancer is non-invasive, meaning it has not spread to surrounding normal tissue (sometimes called carcinoma in-situ). In stage I cancer, the tumor is two centimeters in size or smaller and has not spread outside the breast. In stage II, either:

- There is no tumor in the breast, but cancer is found in the axillary lymph nodes (nodes under the arms); or,
- Tumor is two centimeters or smaller *and* has spread to the axillary lymph nodes; or,

- Tumor is two-to-five centimeters *and* has spread to the axillary lymph nodes; or,
- Tumor is larger than five centimeters *and* has not spread to the axillary lymph nodes
- Number of lymph nodes involved with cancer is not more than three.

About the Roper/NOP Survey

The survey, commissioned by the Society and administered by the Roper Organization (as part of NOP World), was conducted between February 18 and March 28, 2005 via telephone among a national sample of 300 post-menopausal women diagnosed with early breast cancer who met the following criteria:

- Have completed three or more years of adjuvant hormonal treatment (such as tamoxifen) and are still receiving that treatment, or
- Have completed five or more years of adjuvant hormonal treatment (such as tamoxifen) within the past two years.

The sampling error for those currently on treatment is +/-7 percentage points. For those recently completing the treatment, the margin of sampling error is +/-9 percentage points. This survey is subjective and based on the opinions of the patients who participated. This report interprets their results in the context of other published research.

Of 300 completed telephone interviews, 177 were with women nearing completion of the treatment and 123 with those who completed treatment.

About The Society for Women's Health Research

The Society for Women's Health Research is the nation's only not-for-profit organization whose sole mission is to improve the health of women through research. Founded in 1990, the Society brought national attention to the need for the appropriate inclusion of women in major medical research studies and the resulting need for more information about conditions affecting women. The Society advocates increased funding for research on women's health, encourages the study of sex differences that may affect the prevention, diagnosis and treatment of disease, and promotes the inclusion of women in medical research studies. For more information about the Society for Women's Health Research and to obtain a copy of the *Life ABC* report and tip sheet visit <http://www.womenshealthresearch.org/>.

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Note to editors:

The groups that attended the Town Hall meeting include:

Avon Foundation
 breastcancer.org
 Breast Cancer Resource Committee
 CancerCare
 Dana Farber Cancer Institute
 Intercultural Cancer Council
 Men Against Breast Cancer
 Susan G. Komen Breast Cancer Foundation North Jersey Affiliate
 Vital Options
 The Wellness Community
 Y-ME National Breast Cancer Organization