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A Voice for Women with Metastatic Breast Cancer

BY KATHY LATOUR

Women with metastatic breast cancer (MBC) represent a growing number of breast cancer survivors worldwide, living often for many years with the challenges of ongoing treatment, debilitating side effects, and isolation. They advocate for themselves as they are able, but according to Musa Mayer, a metastatic breast cancer advocate, women with metastatic breast cancer around the world need increased attention, resources, and information on clinical trials that may prolong their lives.

Mayer is a member of the Global BRIDGE (Bridging Gaps, Expanding Outreach – Metastatic Breast Cancer Patient Survey) survey steering committee, which has for a number of years been fielding a global survey on behalf of Pfizer to determine the needs, experiences, and attitudes of women living with MBC. At the San Antonio Breast Cancer Symposium, Mayer presented a poster session on the results of the assessment, which surveyed 1,342 women in 13 countries, finding that women with MBC felt they don't receive enough attention, psychosocial support, or information.

“The women came from both developing and developed countries,” she explains. “And the women felt that the attention was going mostly to early breast cancer, which manifested with them not being comfortable being open about their situation.”

Most of the women surveyed had never participated in a clinical trial for MBC, but many had sought information about clinical trials. Mayer says the survey sheds light on this population and their needs.

“What we are doing is putting it out there and communicating that these are the needs,” she says. “These women are hungry for information but they also told us that a good part of the time they cannot find what they need, so it's a call to action on the part of the women around the world.”

Mayer, who was diagnosed with stage 2 breast cancer in 1988, became an advocate for metastatic patients as the women in her support group, and those she had come to know in an online community, began to face recurrence.

“I had joined an online group in 1994 when the Internet was just getting started. It was a lively, thriving group of 1,500 women, and it was a way to promote my memoir, *Examining Myself*. But I forgot about that quickly as these women began having recurrence. They wanted to know if they should leave, and we all encouraged them to stay and share their experiences.”

Mayer developed a heart for these women who were often shunned by other survivors as they began experiencing a survivor's worst fear. Mayer was then asked to write a book about MBC, interviewing 40 men and women living with metastatic breast cancer for her book, *Advanced Breast Cancer: A Guide to Living with Metastatic Disease*, which drew many to her for information and support and prompting the creation of a website that focuses on metastatic breast cancer, AdvancedBC.org.

Mayer moved forward in her work with the National Breast Cancer Coalition and the Department of Defense Breast Cancer Research Program, always keeping in mind those with metastatic disease. In 2001, she applied to the Office of Special Health Issues at the U.S. Food and Drug Administration to become a patient representative and consultant but continues to advocate for women worldwide.

“The ability of the human spirit to adapt to painful and difficult circumstances is there in all cultures,” Mayer says, “but people cannot do it alone. Women need good information.”

This article is a part of CURE's 2009 San Antonio Breast Cancer Symposium coverage. To read more articles from SABCS 2009, visit sabcs2009.curetoday.com.