

FEATURE STORY

## Dancing In Limbo

BY KATHY LATOUR

*More women with metastatic breast cancer are living longer with a better quality of life because of new treatment options, better control of side effects, and more support services.*

Lilla Romeo invites her guests to gather around the dining room table of her elegant 11th floor New York City apartment where the lights of the city at night shine through two glass walls. As her guests settle in, Romeo, 61, points to a room monitor and says that, should they hear baby sounds, it's her 2-year-old granddaughter asleep in a bedroom down the hall.

At the table with Romeo are Ellen Hoffman, 64, and Susan Langley, 60. As the women begin to chat, it's clear this is neither a coffee klatch nor a girls' night out. Instead the three have been brought together by *CURE* to talk about a shared life circumstance they hope will garner more attention from the cancer community and let other women in the same position know they are not alone.

The women all have metastatic breast cancer. Each was diagnosed at a point in the past and underwent treatment for early-stage invasive breast cancer only to become part of what researchers estimate is the 25 percent of women diagnosed with invasive breast cancer who later learn that so-called seed cells from the first tumor traveled to another part of the body and set up shop. [Women whose initial diagnoses show metastatic cancer account for 5 percent of breast cancer cases annually in the United States.]

Indeed, when a woman dies from breast cancer, as some 40,000 will this year, it is almost always as a result of the breast cancer taking over one or more vital organs—most often the liver, lungs, or brain. Breast cancer can also spread to the bones or skin. An estimated 155,000 women are currently living with metastatic breast cancer, a number that is projected to increase to 162,000 by 2011, says Clifford Hudis, MD, chief of the Breast Cancer Medicine Service at Memorial Sloan-Kettering Cancer Center in New York.

Receiving a diagnosis of metastatic, or stage 4, breast cancer, has until the past decade meant difficult treatment that seldom worked well for any extended

period of time, except for a small subset of women who lived significantly beyond the 20-month average. While researchers are identifying more targets, the complexity of variables continues to challenge those whose mission in life has become finding a cure for breast cancer.

At the same time, women living with metastatic breast cancer face their own challenges—many within the breast cancer community itself. Only now are these women beginning to be recognized at pink ribbon events, and few organizations include their issues in discussion or programming.

But today, a combination of factors find women with stage 4 disease living longer—for some, a lot longer—with a better quality of life and more options for treatment that will extend their lives even further. They are active, and many are becoming vocal about the need for the cancer community to include their unique medical and emotional issues in the breast cancer dialogue.

## Stories of Hope - The Women

### **Lilla Romeo**

Lilla Romeo, Ellen Hoffman, and Susan Langley have been living with metastatic breast cancer for eight, four, and one year, respectively.

Romeo, who was initially diagnosed at age 48 in 1995 while living in London, had a lumpectomy and radiation followed by five years of tamoxifen, a type of hormonal therapy. Her cancer returned in the same breast in 2000. Back in New York City by then, she had a mastectomy and began chemotherapy for the recurrence, now stage 3 breast cancer.

Three days before Romeo's last chemotherapy session, a rash appeared on her mastectomy incision—a biopsy showed it was metastasis to the skin. With the cancer moving to another organ, Romeo's cancer was stage 4. Further scans showed no other metastatic sites. A tiny spot on a lung was not thought to be cancer.

A lot had changed since her first diagnosis in 1995, so doctors tested her tumor and found it was positive for HER2, a gene present in normal breast cells that is overly abundant in some malignant cells, which meant a new biologically targeted drug called Herceptin (trastuzumab) could be used. Romeo's initial tumor was estrogen receptor-positive (hormone-sensitive), but as sometimes happens, the stage 4 cancer was estrogen receptor-negative, a change that meant the tumor would not respond to hormonal treatment.

For five years, Romeo received Herceptin with the chemotherapy drug Navelbine (vinorelbine), both administered intravenously. With few side effects, she traveled to England, where she also holds citizenship, and Italy, where she was born. She received treatment at hospitals abroad and lived a full life, going to the gym, celebrating at children's weddings, volunteering on a hotline for breast cancer patients, and becoming an activist for women with metastatic breast cancer. The treatment was working and the cancer on her chest was barely visible.

In 2005, Romeo says her oncologist felt her body needed a “chemo vacation,” so

he took her off Navelbine (she continued taking Herceptin). For eight months, the rash remained stable; then it returned with what Romeo calls “a vengeance.” The Herceptin plus Navelbine combo worked again until February 2007, when the lung lesion, initially thought to be nothing, lit up on her scans, indicating the cancer had spread to her lung. Next, Romeo endured a nine-month roller coaster of drugs from the arsenal that has become available in the past 15 years.

Her oncologist tried three different drug combinations, and with each new cocktail, Romeo waited three months before scans showed if it was working. In the meantime, Romeo walked the all-too-familiar tightrope of waiting, watching, and hoping while the cancer grew and the list of possible drugs shrank.

On the night we gather Romeo has just learned that Abraxane (paclitaxel reformulation), the fourth option used by her oncologist, is working. Scans show dramatic improvement and nearly complete resolution in some areas. She has received a reprieve.

When Romeo begins ticking off the drugs her oncologist tried, there is a tense silence in the room as both Hoffman and Langley listen intently to what they know could very well be their future.



Langley, Romeo, and Hoffman (from left) each have different styles for coping with metastatic cancer. Photo by Ryan Ashby

### **Ellen Hoffman**

It had been 22 years since her initial diagnosis when Hoffman was diagnosed with a recurrence in 2005. For the artist and retired educator, it was a bone scan that showed multiple lesions throughout her body.

Hoffman’s tumor was estrogen receptor-positive and she began hormonal treatment with Femara (letrozole) for six months before beginning a trial of Femara and Avastin (bevacizumab) for six months. Then it was tamoxifen followed by Aromasin (exemestane). She has now been on oral Xeloda (capecitabine) since July 2007, and her disease is stable. She also sees an orthopedist, who monitors lesions in her hips, pelvis, and femur to be sure she is not in danger of fractures and to determine if she needs further radiation.

Shortly after the recurrence was discovered, Hoffman retired with disability from her teaching and staff development position, a move she says measurably

reduced her stress. She remains active as an artist, creating new work and exhibiting her large-scale drawings while also serving as treasurer in an artists' collaborative.

### **Susan Langley**

After her stage 2 breast cancer diagnosis in 1998, Langley received Adriamycin (doxorubicin), Cytosan (cyclophosphamide), and Taxol (paclitaxel).

In December 2006, Langley, now retired from CBS News Corporate and Records, experienced excruciating pain in her upper right arm. After an X-ray showed the bone was broken, further scans revealed the breast cancer had spread to the bones in the left shoulder and right hip. (Bone metastasis increases the risk of fracture.) Because her cancer was estrogen receptorpositive, she began the oral hormonal drug Aromasin with monthly intravenous injections of Zometa (zoledronic acid) to protect her bones.

Her cancer is now stable, and she has become an advocate for metastatic breast cancer patients, appearing in a print advertisement for Pfizer Oncology and serving as a patient representative for AstraZeneca.

Langley says when her cancer recurred she didn't understand the severity at first. A social worker she knew set her straight when Langley began talking of getting through this bout the way she had before.

"She explained to me that metastatic breast cancer can't be cured, it can only be controlled." It was a shock, but Langley says she is an optimistic person.

She finally accepted the magnitude of a stage 4 diagnosis, she says, when she returned to the support group she had attended previously and the facilitator waved her away when she saw her entering the room. The facilitator explained that the group was for early-stage breast cancer patients; there was a separate support group for stage 4 patients.

Langley then understood she represented the worst fear of women newly diagnosed with breast cancer—that the cancer could recur.

### **Focusing on Life**

As we gather, each of the women is in a good place with treatment and has stable disease. Romeo continues work on the steering committee of the Metastatic Breast Cancer Network, an advocacy organization started by a small group of women being treated at New York's Memorial Sloan-Kettering Cancer Center in 2004 who came together in a support group facilitated by clinical social worker Roz Kleban.

Kleban has been working with breast cancer patients for more than 20 years and facilitates two metastatic support groups at Sloan-Kettering—one for women over 40 and the other for the under-40 crowd. The "babies," as she calls them, have significantly different issues than the older women.

““ It's like you have a radio in your head that's on at all times distracting you from life. And you can't turn the radio off, but you can turn the volume down as low as possible. ””

—Roz Kleban

While Kleban says fewer women with metastatic disease have the energy to become advocates, she has been excited to see the MBCN grow, and she has been instrumental in developing an annual meeting for women with stage 4 disease where they can gather and hear the latest information on treatment and psychosocial issues.

The first conference, held at Sloan-Kettering in 2006, featured expert physician speakers, including Sloan-Kettering's internationally known breast cancer specialist Larry Norton, MD, Kleban says.

“We were thinking, ‘Who is going to come to this?’ So we were thinking we would get 60 people and then we realized we'd get 90 because of Norton,” says Kleban. The event ended up drawing more than 300 women from 16 states and Canada and was a remarkable event for the women, says Kleban. “They are no longer the forgotten community. They can stand proud. They would come into the room and look around at a mob of magnificent- looking, healthy women.”

The mission of MBCN is to change the way metastatic breast cancer is viewed by the breast cancer community, says Romeo, who has become very knowledgeable about the disease and has testified in Washington, D.C., before committees exploring a number of cancer- related issues.

Romeo's goals mirror those of MBCN and include educating those who think of metastatic breast cancer as an immediate death sentence, encouraging drug companies to develop drugs that extend life and improve quality of life, and advocating for broader admission criteria for clinical trials. As part of the program to bring awareness, the MBCN named October 13 Metastatic Breast Cancer Awareness Day, receiving official recognition from the city of New York and Mayor Michael Bloomberg in 2007.

Romeo also volunteers on the helpline for SHARE, a nonprofit organization in New York City that supports women with breast or ovarian cancer, saying that, ironically, the work does not depress her but is very gratifying. “I pick up the phone and we talk. They feel better and I feel better.”

Kleban says support groups help women understand and cope with the losses they suffer as a result of the disease. When diagnosed with early-stage breast cancer, women can hold on to the fact that when treatment is over, they can pick up their life exactly as it was before, she says. “With metastatic disease, it's a series of losses. Not being able to work because of side effects of illness or treatment, or extreme emotional confusion.”

Romeo says one of the most emotional times is when treatment stops working. “It's very difficult emotionally to handle the roller coaster of trying one drug after the other, hoping for response.

“We know how to compartmentalize and our defense system kicks in,” she says. “We distract ourselves as much as possible with volunteer work or friends. We go to movies, read, or do whatever we can to get through the day in one piece.”

Kleban agrees that women must decide what in their lives has meaning and pursue that—living each day to the fullest. “I tell women that it’s like you have a radio in your head that’s on at all times distracting you from life,” Kleban says. “And you can’t turn the radio off, but you can turn the volume down as low as possible. That should be the goal.”

Primary relationships are of great importance to each of the women as they recount the changes the metastatic diagnosis has meant for them.

Hoffman talks about facing a dramatic reminder of her physical condition the day after our meeting, when she and her husband of 28 years will move from the fourth-floor walk-up apartment they have shared for 25 years to one with an elevator—and triple the rent. Walking up stairs multiplies the stress on her bones, she says, and her physician is concerned she will break a bone weakened by cancer while climbing stairs.

Langley says she doesn’t have difficult days and remains incredibly optimistic, even feeling like an imposter because she has so few side effects from the treatment and she feels well.

“Time is running out, but it’s nothing to do with cancer,” she says. “I have too much to do and don’t want to die before I have done it all. You want the last check to bounce. ”