



Chronicles of Hope: Ute Bankamp

The Chronicles of Hope are the *real life* stories of those helped by Susan G. Komen for the Cure's commitment to the care, research and understanding of breast cancer. These are their—and our—stories.

Ute Bankamp woke up one morning in 2001 with a single, painless symptom - an enlarged breast that she first thought was a sign of pregnancy. Just two weeks after losing one of her own patients to inflammatory breast cancer (IBC), she received her own diagnosis of IBC at the age of 32.

Inflammatory breast cancer is a rare but aggressive form of the disease with main symptoms of swelling (inflammation) and redness of the breast. Despite the overwhelming implications of the diagnosis, Ute says she knew she had "good luck, very, very good luck" because there was no evidence of metastasis, which is present in 20 to 30 percent of IBC patients at the time of diagnosis.

Ute is an obstetrician who lives in Germany where there is no standard recommendation for annual mammography. Ute reports that women may be screened between the ages of 50-69, however it is more common for a woman to be sent to a radiologist after her doctor has detected a problem. Even in the U.S., Ute wouldn't have been considered a candidate for mammography at the age of 32. Even if she had, IBC is difficult to see on a mammogram because it is often spread throughout the breast and does not always present with a lump.

Ute proceeded with a rigorous treatment plan that included a mastectomy and a plethora of treatments including off-label use of trastuzumab (Herceptin). Ute's active treatment continued for over six years.

As a young survivor, Ute dealt with a wide range of survivorship issues from learning how to maintain her career, self image and fertility. Ute remembers an instance when another young doctor who considered her a colleague couldn't even look her in the eye and had difficulty speaking with her. She says simply, "It hurt. The conversation was very painful." In addition, the once self-proclaimed work-a-holic had to stop working in order to deal with all of the treatments and side effects. This drastic change in lifestyle was a factor in her decisions to begin psychotherapy and use an anti-depressant.

Ute wanted to join a support group, but she quickly found that the other patients were significantly older than she was and many were not experiencing the same kinds of issues. Even though she wasn't able to find the support she wanted in group therapy, she was encouraged by how many survivors she met. She didn't realize how many women survived because working in the hospital, she only saw the worst cases of breast cancer. It became very difficult for Ute to work with these patients while going through her own treatment.

Another issue young survivors often struggle with is self-image. Most IBC patients are not good candidates for immediate breast reconstruction, which can be disappointing news. Delayed reconstruction, however, may be an option, particularly in patients who have a good response to



Survivor Ute Bankamp

Diagnosis Inflammatory Breast Cancer

Years of Survivorship 9

"I had the worst case scenario, but I had the chance to survive and I am very grateful and happy about that."

The Susan G. Komen for the Cure® promise is to save lives and end breast cancer forever.

Learn more at www.komen.org. ©2011 Susan G. Komen for the Cure® The Running Ribbon is a registered trademark of Susan G. Komen for the Cure®.

chemotherapy. Ute thinks about reconstruction, but knows that she is not an ideal candidate for the surgery.

Despite all of the other life changing effects of her IBC diagnosis, the single most important issue for Ute was fertility. She remembers feeling angry with herself for not having a child earlier, particularly when several of her friends had babies around the time of her diagnosis. Her regret about not having a baby was transformed into the hope of becoming pregnant in the future. She says that the goal of having a baby “helped keep her alive” even though she didn’t know if it would ever be possible.

“Don’t give up hope...don’t panic!
You do have a chance to survive.”

Miraculously, a few months after ending all of her treatment, Ute became pregnant with a son. She had a healthy pregnancy and even successfully breastfed her baby with the unaffected breast. While she sometimes worries about what would happen to her son if she had a recurrence, she spends most of her time concentrating on being a good mom and taking care of herself.

Today, Ute’s life is very different from her pre-IBC existence. She works only occasionally, spends lots of time with her thriving son and makes time to exercise regularly. Looking back, Ute is grateful for the enormous support of her loving husband as well as many friends, family members and colleagues. She states that she had very different plans for her life, but that “going the long way around has enriched my life enormously.”

INVOLVEMENT WITH KOMEN

While undergoing treatment in 2003, Ute found out about her local Komen Affiliate, Susan G. Komen Deutschland, and signed up with her sister for her first Race for the Cure®. She wanted to run with other survivors, but couldn’t decide if she wanted to advertise her survivorship by wearing a pink t-shirt or be more anonymous in a white t-shirt. Ute remembers that day, saying, “I felt very happy that I decided to take the pink shirt because it was a very great race and the experience was so good...” She was so inspired by the Race that she became a volunteer for the Affiliate.

In 2004 Ute became a member of the Grant Making Committee. Later she was appointed the Grant Committee Chair and even served on the Board of Directors. She continues to participate in Komen events when she can.

KOMEN’S IBC RESEARCH INVESTMENT

Komen for the Cure has invested over \$8.5 million in IBC research since 1995 when we granted Dr. Sofia Merajyer \$123,000.00 to learn more about the biology of the disease. Since then, we’ve funded six additional grants including a large, multi-year, multi-institutional American Airlines Susan G. Komen for the Cure Promise Grant. Drs. Fredika Robertson and Massimo Cristofanilli are working together on the \$7.5 million project to study the biology of IBC and use these insights to develop new ways to diagnose IBC more rapidly and accurately and to develop new targeted therapies to help patients fight this aggressive disease.

Other areas our grantees have focused on are resistance to treatment and the relationship between inherited genes and IBC. For more information about cancer risk, including IBC, visit the Understanding Breast Cancer section on www.komen.org.

May 2011