

germany's 'busenfreunde'

A new generation of breast cancer activists challenges the status quo

When journalist Ursula Goldmann-Posch was diagnosed with Stage II breast cancer at the age of 46, she did not know that good hospitals in Germany perform breast-conserving surgery in nearly 80 percent of all cases. A candidate for lumpectomy, Goldmann-Posch nevertheless lost her left breast within days of her diagnosis.

When librarian Gudrun Kemper discovered, at the age of 39, that she had breast cancer, she did not know that, according to experts, even Germany's best-known hospitals frequently offer no counseling, the wrong chemotherapy and inappropriate forms of surgery.

When I was diagnosed with breast cancer at age 50, I had no idea I would chance upon one of Germany's best breast cancer centers—one that utilizes a multidisciplinary approach and offers highly specialized care.

I was lucky. But should breast cancer treatment in one of the world's richest nations be left almost entirely to chance?

That seems to be what is happening now in Germany. Though everyone has health insurance, provided by employers and the government, our country takes a sad first place in European breast cancer death statistics: Out of the 46,000 women who are diagnosed each year, 19,000 eventually die of the disease. Our five-year survival rate is below the European average. And here's another shocking comparison: Fifteen years after diagnosis, only 41 percent of German breast cancer patients are still alive. In the US, that figure is 58 percent.

Some reasons for Germany's poor performance are easy to identify: there is no public health initiative that recommends mammographic screening; diagnosis and treatment do not follow the practice guidelines established by the European Society of Mastology; and quality management in medical care has just begun to get off the ground.

Ursula Goldmann-Posch, Gudrun Kemper and I refused to accept this situation. In 1999, along with other



Mamazone members with researcher Axel Ullrich

survivors, we decided to found an advocacy group called Mamazone. (The name plays on the Latin word for "breast" and on the Greek myth of the Amazon warriors.)

We're the first such group of its kind in Germany, where breast cancer organizing has focused almost entirely on support groups. Mamazone has more than 600 members who are given access to results of recent clinical studies and can actively join the group's fight for better healthcare policy.

Mamazone also confers an annual award to the country's most ambitious breast cancer researcher. (The award's name, "Busenfreund," comes from the German word for "bosom buddy.") We've created a system of patient-driven tumor banks, so that survivors' tumor tissue can be utilized by researchers and individual women alike. This summer, we also made news with provocative T-shirts that read: "Bosom, tits, boobs, knockers, breasts. Cancer makes no distinction. Do you know your risk?"

Ursula Goldmann-Posch, Gudrun Kemper and I are friends, partners, "mamazones" and fighters in the battle against breast cancer. Together, our group hopes to improve the quality of care for women with breast cancer, encourage medical research, and give survivors a stronger voice. Our struggle has just begun. ❄

by ulla ohlms