

<< Choices for the High-Risk Woman >>

BY KATHY LaTOUR

Selma Schimmel was diagnosed with breast cancer 20 years ago at age 28, only three years after losing her mother to ovarian cancer. As a result of her experience, Schimmel founded Vital Options®, the first organization in the United States for young adults with cancer. Today she operates Vital Options International TeleSupport Cancer Network, a global nonprofit cancer communication, advocacy, and support organization that produces the nationally syndicated cancer talk show *The Group Room* in association with Premiere Radio Networks.

In September of this year, during National Gynecologic Cancer Awareness Month, Schimmel was diagnosed with early-stage ovarian cancer—found, ironically, during a prophylactic procedure to remove her ovaries.

Schimmel says she is struggling with the lack of treatment for early-stage ovarian cancer since it is seen so seldom, which is one reason why she will be constantly evaluating the results of her Taxol/carboplatin regimen to keep neurotoxicity to a minimum.

"There is controversy over whether to treat early-stage ovarian," she says, "so they have to treat us as if we have more widespread disease."

Schimmel says she spent years considering the prophylactic procedure while listening to those urgently in favor of it and those less concerned, while being screened on a regular basis.

"I was having ultrasounds and blood tests every three months. In the last year, I developed an ovarian cyst that was not suspicious in nature, but as it lingered, it helped me decide the time was right to just be proactive," Schimmel says. "My tumor markers had always been normal, rising one point above normal the night before surgery."

Schimmel says that while gynecologic oncologists and geneticists urge prophylactic surgery in BRCA-positive patients, it's equally important for medical oncologists to agree. Even leading up to her own surgery, Schimmel says some asked why she was doing it sooner rather than later, since having the gene did not mean she would ever get ovarian cancer.

Schimmel says the medical community needs to provide a united opinion to women struggling with such issues. "My concern for all of us is that as the human genome continues to reveal the genetic profile of disease, society needs a real comprehension of the information. We need to figure out how to change our behavior and actions in response to new science and technology."

About 10% of ovarian cancer cases have been linked to genetics, typically through susceptibility genes. Located on chromosome 17, the



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two BRCA genes are the first to be identified as carriers of a predisposition to breast and ovarian cancers. When a woman has a mutation in either *BRCA1* or *BRCA2* genes, she is at higher risk to develop one of these cancers.

Women with a familial history of ovarian cancer may benefit from additional testing if they meet certain criteria. The American Society of Clinical Oncology recommends cancer predisposition testing if: 1) the person has a strong family history of cancer or very early onset of the disease; 2) the test can be adequately interpreted; and 3) the results will influence medical management.

To those who asked Schimmel why she didn't undergo surgery sooner, she wants to remind them that letting go of body parts is difficult and people do things when they are ready, emotionally, physically,

and psychologically. "We identify with our body parts, often symbolically. Other issues come up for women who have not had children. Women need help to make choices. It's easy to say what we should do, but it's hard to decide to do it and when to do it."

Schimmel says this time she will have supportive care drugs that were not available 20 years ago when she underwent chemotherapy for breast cancer. Her oncologist addressed her concerns about the side effects and she knows that unlike the first time she had chemotherapy, she will benefit from anti-nausea drugs, as well as those to help her keep her blood counts up to avoid disrupting her chemotherapy cycle. For psychosocial help, she will rely on what she encourages her listeners to do.

"Communication is the bottom line, and I will communicate often and loudly. Cancer is the theme of my work every day, so I am immersed in it, but I am also blessed with a strong circle of support and love."

Schimmel says she will share her journey on *The Group Room*, which reaches more than half a million radio listeners each Sunday throughout the United States, but it will only be a part of the show. Listeners can tune in via XM Satellite Radio or the Internet simulcast at www.vitaloptions.org, where the show is also archived. Listeners can join discussions on *The Group Room* by calling 800-GRP-ROOM (477-7666) or by e-mailing info@vitaloptions.org.

The National Ovarian Cancer Early Detection Program helps identify women who are at risk for developing genetically related ovarian cancer through ongoing research studies.

Women interested in participating in one of the group's clinical trials can visit the National Ovarian Cancer Coalition's website at www.ovarian.org. □