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# Recovering from loss

The Breast  
Cancer Recovery  
Foundation  
helps women  
not only  
survive, but  
thrive



*Trudy A. Karlson, PhD, and David L. Weber, MD*

**C**an a breast cancer diagnosis offer anything uplifting to women unlucky enough to hear this news from their physicians?

Yes.

As donors and volunteers for the Breast Cancer Recovery Foundation, Inc., we have witnessed the remarkable capacity of the human spirit to grow amidst the deepest loss. We have seen vital and joyous women, more vibrant than many with much longer life expectancies. We have also seen good friends die too soon and too young, having lived their final years more fully than we could ever have imagined.

The Breast Cancer Recovery Foundation, Inc. (BCRF) is a Wisconsin organization founded in 1997 by Ann Haney to share her vision that life can be rich even with a breast cancer diagnosis. Haney believed

that women could come together at retreats and be relieved of the day-to-day responsibilities of their lives. She thought that breast cancer patients and survivors could help each other, that at retreats they could experience the healing of nature, learn new ways of coping with the disease, and share their stories. During her time as Health Officer for the state of Wisconsin, Haney had come to know the problems of women with breast cancer. After her own diagnosis, and while still working full time as an executive for Dean Health Systems in Madison, she set about bringing her vision to life by developing the BCRF's Infinite Boundaries retreats.

Difficult quality-of-life issues frequently surface with the diagnosis and treatment of breast cancer. Some women feel physically violated after their surgery and betrayed by their bodies. Many feel a loss of their femininity. Others feel overwhelmed with guilt and anger compounded by a fear that the cancer will come back.

BCRF Infinite Boundaries retreats are designed by breast cancer survivors for breast cancer survivors to

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Dr Karlson is a Senior Scientist at the University of Wisconsin-Madison and has served as a volunteer at the Breast Cancer Recovery Foundation's Infinite Boundaries retreats. Doctor Weber is a family physician with Dean Medical Center in Sun Prairie, Wis.



*"Prayer flags" like these greet participants at retreats.*

allow them to discuss and heal the pains of their diagnoses. Held on Madeline Island in Lake Superior and other scenic spots, retreats offer outdoor adventures, spiritual reflection, creative arts, and the sharing of joys and concerns with other women. Activities are designed to release pent-up emotions and to lead to restored confidence in one's body. Haney described it this way:

"These women have been giving, giving, giving... We provide an environment where they can sort things through, where they can handle the physical demands. We take this into a new space and we talk about the big issues—trust, anger, and fear. Their food is prepared, their beds are made. It's no luxury, but it's what they need at the time: everything to be done just for them."<sup>1</sup>

First piloted in the fall of 1997, the retreats have helped hundreds of women from Wisconsin and many other states. The social support they receive helps put their experiences in perspective, and provides a safe and secure environment for them to try new activities, share—perhaps for the first time—their deepest fears and know that they are not alone. As one woman said, "It is just nice to be around

other women like me. I see the fear on the faces of my children and husband. Then I have to be strong for everyone." Another woman said: "I can't fully explain the bonding, but you share so much of your souls with each other. And you give each other strength. You arrive as strangers, and I left feeling like I had 20 sisters."

Each retreat is structured to create challenges and opportunities within a protective and supportive envelope. When women arrive, they are greeted with colorful "prayer flags" made by previous participants, reflecting women's deepest longings and hopes: "Celebrate Life," "I, too, can fly free," and "Don't count the days, make the days count."

Retreats allow women to share practical information as well. They discuss their experiences with breast reconstruction, prostheses, chemotherapy, radiation, and clothing suppliers. They exchange tips about coping with hormonal changes. They show each other their scars.

An important part of retreats is that the women learn from each other. Sharing with other women at the retreat helps put their experiences in a new perspective. After walking a labyrinth at the retreat one woman said, "I walked thinking that good health was my goal but what I found at the center was what I



*Retreat participants pose for a group photo.*

needed—the support of my sisters and friends.”

Another woman said, “You can benefit so much from what seem like offhand conversations. When I was kayaking in Lake Superior with another woman, we glided by trees hanging off the edge of the cliffs, their roots exposed. And I said, ‘That’s not the way a tree is supposed to live, with its roots exposed.’ She said, ‘You don’t always need an optimal situation in order to survive.’ I realized what a wonderful image that was for many of us who have this disease. And I’ve thought of it so often ever since.”

Each retreat concludes with a “Letting Go” ceremony. Women are asked to bring something from nature that represents what they’d like to leave behind. During the ceremony, they release their fears, guilt, failed relationships, and worrisome obligations into the waters of Lake Superior. It is a scene of celebration with many hugs and many tears.

In 1999, researchers affiliated with the Department of Psychiatry at the University of Wisconsin Medical School designed a study to measure psychosocial changes in the women who attend Infinite Boundaries retreats. The first phase of the research (1999-2000) studied women participants; the second phase compared participants to randomized controls (2001-2002). Compared to medically matched controls, breast cancer survivors who attended an Infinite Boundaries retreat reported significant decreases in stress and anxiety, significant increases in positive affect (the ability to feel joy), and significant improvements in body image. While not reaching the level of statistical significance, depressive symptoms among participants were also decreased compared to the control population. Survivors who attended a retreat reported significant improvement in their self-image, general well-being, and functional well-being.<sup>2</sup>

BCRF tries to make it possible for any woman to attend. Over 95 percent of women on retreats receive financial assistance. And many other accommodations are made. One woman wrote seeking help. “My sister...is a breast cancer survivor (three times) and is deaf. This leaves little chance for her to communicate her feelings, and fears.” BCRF staff arranged for her sister to attend the retreat and found two interpreters who teamed up to sign for her during the four days of discussion, conversation, and activity. The interpreters were so moved by the experience that they have volunteered to return whenever needed.

Additionally, BCRF recently developed a retreat for African American women—and instead of the

hoped-for 12 participants, 30 women attended.

#### Epilogue

Ann Haney died May 31, 2003. We will grieve her loss for a very long time, but she prepared us to carry on without her and we will. Each year, more women are diagnosed with breast cancer and face challenges to their lives and spirits. It is testament to Ann’s



*Breast Cancer Recovery Foundation Inc. founder, Ann Haney*

courage and wisdom that until the last days of her life she gave unstintingly of herself to make her vision real. The Breast Cancer Recovery Foundation, Inc. will be a fitting legacy—helping women to recover and be loved and uplifted in the face of this disease.

In addition to Infinite Boundaries retreats, the BCRF also sponsors educational forums and outreach programs for breast cancer survivors and their care givers, including an annual Sharing the Knowledge conference on the latest breast cancer research, and many other special events. More about the Infinite Boundaries retreats and other activities can be found at [www.bcrf.org](http://www.bcrf.org). The office phone is 608.821.1140 and fax is 608.821.1141; e-mail is [info@bcrf.org](mailto:info@bcrf.org); mailing address: Breast Cancer Recovery Foundation, Inc., PO Box 5070, Madison, WI 53705-0070.

#### References

1. Interview, *Madison Magazine*, October 2001.
2. Teresa Woods, PhD, Department of Psychiatry University of Wisconsin-Madison.



The mission of the *Wisconsin Medical Journal* is to provide a vehicle for professional communication and continuing education of Wisconsin physicians.

The *WMJ* (ISSN 1098-1861) is the official publication of the Wisconsin Medical Society and is devoted to the interests of the medical profession and health care in Wisconsin. The managing editor is responsible for overseeing the production, business operation and contents of *WMJ*. The editorial board, chaired by the medical editor, solicits and peer reviews all scientific articles; it does not screen public health, socioeconomic or organizational articles. Although letters to the editor are reviewed by the medical editor, all signed expressions of opinion belong to the author(s) for which neither the *WMJ* nor the Society take responsibility. The *WMJ* is indexed in Index Medicus, Hospital Literature Index and Cambridge Scientific Abstracts.

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