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## **SURVIVORS JOIN MOVEMENT TO IMPROVE BREAST CANCER OUTCOMES**

*Landmark Patient Registry Will Identify Psychosocial Needs of Women With Breast Cancer*

**WASHINGTON** — Millions of women with breast cancer now have a new tool to help fight this deadly disease. The Cancer Support Community's Research and Training Institute announced today the launch of its nationwide [registry for breast cancer survivors](#).

The first of its kind in breast cancer, the registry will monitor survivors who have volunteered to share their breast cancer experiences with researchers to help them better understand the distress women experience during their cancer journey.

The registry, known as the *Breast Cancer M.A.P. (Mind Affects the Physical) Project*, aims to recruit more than 1,000 survivors to answer questions about the emotional and social needs that accompany a breast cancer diagnosis, on an annual basis. Study findings will be shared with the breast cancer community in a yearly index highlighting trends and key learnings and providing recommendations for innovative ways to address the impact of the disease throughout the course of treatment and survivorship.

"Research shows that the right emotional support can have a significant impact on quality of life for breast cancer survivors, and often reduce troublesome symptoms and improve health," said Barbara L. Andersen, Ph.D., professor, department of psychology, Ohio State University. "This movement will assist oncologists and patients in better understanding the importance of managing distress to fight the disease."

A recent survey from the Cancer Support Community showed that four out of five women affected by breast cancer experienced some form of distress due to their cancer and more than half felt their emotions have been misunderstood. These data reinforce findings from the Institute of Medicine (IOM), which firmly established the need to better understand and improve the emotional and social needs of breast cancer survivors through a series of evidence-based reports. Additionally, a study previously published in the journal *Cancer* provided evidence that emotional support improved psychological and behavioral outcomes among breast cancer

patients, and may also increase their chance of survival, decrease their risk for recurrence, and decrease their risk of dying from other conditions.

“By listening to the shared experiences of breast cancer survivors, we can bridge the gaps in our knowledge and help inform new resources that support their most critical needs,” said Joanne Buzaglo, Ph.D., senior director of research at the Research and Training Institute of the Cancer Support Community. “Our success depends greatly on the participation of breast cancer survivors. As the registry grows, so will our ability to change the breast cancer experience.”

Breast cancer survivors are able to participate in the registry by signing up online at [www.breastcancerregistry.org](http://www.breastcancerregistry.org) or by calling 1-888-MAP-CSC9 (1-888-627-2729). Oncologists, primary care physicians and oncology social workers interested in learning more about the registry should visit the website for more information.

“Dealing with my cancer has been challenging at every stage of the disease - from the time I was diagnosed, after treatment stopped and when the cancer spread,” said Paula Benoit-Falwell, a breast cancer survivor. “My hope is if enough women like me sign up for this registry and share their experiences, we’ll be able to better understand the benefits of emotional support and create resources that will help women along their journey to healing.”

Thanks to great scientific advances and breakthroughs, more women than ever are surviving breast cancer. In fact, there are now more than 2.5 million breast cancer survivors in the United States. With the rise in survivorship, there is a need to recognize and identify the new challenges beyond those experienced at diagnosis and during treatment. Made possible through a generous grant from The Breast Cancer Fund of National Philanthropic Trust, the *Breast Cancer M.A.P. Project* was developed to tackle this very challenge.

#### **About the Cancer Survivor Registry *Breast Cancer M.A.P. Project***

The Cancer Survivor Registry’s *Breast Cancer M.A.P. (Mind Affects the Physical) Project* is a movement to identify and address the emotional and social needs that accompany a breast cancer diagnosis. By joining this first-of-its-kind registry and sharing their breast cancer experience, women have a unique opportunity to help researchers better understand the full impact of breast cancer and ultimately discover innovative ways to improve the cancer journey for millions. Initiated by the Cancer Support Community’s Research and Training Institute, the *M.A.P. Project* is made possible through a generous grant from The Breast Cancer Fund of National Philanthropic Trust.

#### **About the Research and Training Institute at the Cancer Support Community**

The Cancer Support Community’s Research and Training Institute examines the critical role of social and emotional support for those living with cancer and studies the distinctive needs of survivors and caregivers throughout each phase of the cancer experience, as well as post treatment. Focused on research and education, this vibrant resource enables the Cancer Support Community to conduct peer-reviewed research, sponsor patient and caregiver forums, host retreats and direct state-of-the-art training programs for health care professionals.

#### **About the Cancer Support Community**

Backed by evidence that the best cancer care includes emotional and social support, the Cancer Support Community offers these services to all people affected by cancer. Likely the largest professionally-led network of cancer support worldwide, the organization delivers a comprehensive menu of personalized and essential services. Because no cancer care plan is

complete without emotional and social support, the Cancer Support Community has a vibrant network of community-based centers and online services run by trained and licensed professionals. For more information, visit [www.cancersupportcommunity.org](http://www.cancersupportcommunity.org).

In July 2009, The Wellness Community and Gilda's Club joined forces to become the Cancer Support Community. The combined organization provides high-quality psychological and social support through a network of nearly 50 local affiliates, more than 100 satellite locations and online.

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