



**FOR IMMEDIATE RELEASE**

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**CANCER RESEARCH MOVEMENT TO IDENTIFY SOCIAL AND EMOTIONAL NEEDS  
OF PEOPLE LIVING WITH CANCER**

*First-ever registry of its kind provides outlet for people with cancer*

**WASHINGTON - (March 21, 2013)** - The Cancer Support Community's Research and Training Institute launched a nationwide registry today that will help researchers better understand the impact of cancer on people who have or have had this disease.

Called the Cancer Experience Registry<sup>SM</sup>, this first-of-its-kind research endeavor will collect the experiences of people who have volunteered to share their cancer journey in a 75-question survey and will connect them to a network of support and resources.

The information collected from the registry will be used to develop programs to more effectively address the emotional and social needs of people affected by cancer. The Cancer Support Community's Research and Training Institute will publish an annual index of findings to share the research with the cancer community at large.

"We are eager to advance the cancer community's understanding of the full social and emotional impact of cancer through the Cancer Experience Registry. The insights from this research venture will help to identify the often-overlooked needs of people with cancer and their families," said Kim Thiboldeaux, President and CEO of the Cancer Support Community.

The survey consists of items that measure the social, emotional, spiritual and financial effects of cancer on the person diagnosed as well as his or her family. After completing the registry profile and questionnaire, members will be able to compare their responses with others in the community and will be connected to online and community-based educational resources relevant to their concerns and interests.

The registry also includes separate projects designed specifically for people who have experienced breast cancer and metastatic breast cancer. These specialized communities will help to further identify the unique needs of these two groups. The Cancer Support Community will be launching other cancer-specific projects in the near future, including one for multiple myeloma to launch later this spring.

The Cancer Experience Registry builds on the success of the Cancer Support Community's pioneer registry, The Breast Cancer M.A.P. (Mind Affects the Physical) Project, which since inception has collected the experiences of more than 3,600 people who have been diagnosed with breast cancer.

Eighty-seven percent of respondents in the inaugural Breast Cancer M.A.P. Project reported that at least one social, physical or emotional issue was a moderate to very severe problem. The Institute of Medicine (IOM) 2008 report, "Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs," identifies psychosocial support as a key component of complete cancer care. The full findings of the inaugural Breast Cancer M.A.P. project are available online at [www.CancerSupportCommunity.org](http://www.CancerSupportCommunity.org).

"Breakthroughs in cancer treatment are helping people to live longer than ever before. As a result, the cancer community is becoming increasingly aware of the importance of social and emotional support throughout the cancer journey," said Joanne Buzaglo, Ph.D, VP of the Cancer Support Community's Research and Training Institute.

Anyone who has been diagnosed with cancer at any time is invited and encouraged to join the registry by visiting [www.CancerExperienceRegistry.org](http://www.CancerExperienceRegistry.org).

The Cancer Experience Registry is supported by generous grants from Celgene Corporation, Eisai Pharmaceuticals, Onyx Pharmaceuticals and Genentech.

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

The mission of the Cancer Support Community (CSC) is to ensure that all people impacted by cancer are empowered by knowledge, strengthened by action and sustained by community. In 2009, The Wellness Community and Gilda's Club joined forces to become the Cancer Support Community. The combined organization, with more than 50 years of collective experience, provides the highest quality social and emotional support for people impacted by cancer through a network of over 50 licensed affiliates, more than 100 satellite locations and a vibrant online community, touching more than one million people each year.

Backed by evidence that the best cancer care includes social and emotional support, the Cancer Support Community offers these services free of charge to men, women and children with any type or stage of cancer and to their loved ones. As the largest, professionally led nonprofit network of cancer support worldwide, the Cancer Support Community delivers a comprehensive menu of personalized and essential services including support groups, educational workshops, exercise, art and nutrition classes and social activities for the entire family. In 2011, CSC delivered more than \$40 million in free services to patients and families. The Cancer Support Community is advancing the innovations that are becoming the standard in complete cancer care. So that no one faces cancer alone.®

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