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**THE COSTS OF CANCER REMAIN HIGH,  
YET PATIENTS ARE NOT PREPARED TO DISCUSS TREATMENT OPTIONS**

*The Cancer Experience Registry identifies needs of people living with cancer*

**PHILADELPHIA** – (October 22, 2014) – A study released today by the international nonprofit Cancer Support Community found that more than half of patients with cancer feel unprepared to discuss treatment options with their medical team, a significant finding given the high burden patients with cancer carry across a number of dimensions.

In particular, the research found that patients are living with additional toxicities that include, yet also extend beyond, the physical. The report found:

- **Challenges around the cost of cancer care:** About one-third of patients said that they had to reduce their grocery expenses, and one-third said that they had depleted their savings due to cancer-related costs. 45 percent of patients with metastatic breast cancer lost their jobs – about half involuntarily – due to cancer.
- **Concerns about long-term side effects:** nearly half (42 percent) of patients are seriously concerned about nutrition, and about a third (32 percent and 34 percent, respectively) are seriously concerned about fatigue and exercise.
- **Ongoing need for social and emotional support:** 37 percent of patients have serious worries about the future, and 35 percent have serious financial worries.

“Elevating the Patient Voice,” the 2014 Annual Report of the Cancer Experience Registry, looked at 3,500 of the more than 7,300 people in the Registry to identify social, emotional and financial needs of people living with cancer. Highlights of the study presented today are available online [here](#).

“We hear over and over that patients feel uncomfortable bringing up their issues with their doctors. They don’t want to bother them, or be seen as a ‘bad patient.’ We put a lot of effort into asking questions that are sensitive to our population – and our respondents often tell us, ‘no one ever asked me that before,’” said Joanne Buzaglo, Ph.D., Vice President of Research and Training of the Cancer Support Community.

This first-of-its-kind Registry consists of items that measure the total cancer experience, including the physical, 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 can compare their responses with others in the community and can be connected to online educational content relevant to their concerns and interests.

“I was in so much emotional distress, I cried all the time....It made a huge difference when I told my manager what was happening, and he told me that he was a melanoma survivor. He said my job was safe, and I should do whatever I needed to take care of my cancer,” said Linda P., a member of the

Registry who was diagnosed with breast cancer in 2010, two weeks after starting a new job – after having been laid off for several months. “I signed up for the Cancer Experience Registry to give back to other women going through what I did, let them know that they can get through it.”

The Registry also includes specialized communities designed specifically for people who have experienced breast cancer, metastatic breast cancer, multiple myeloma, chronic myeloid leukemia and more to come. These specialized communities will help to further identify the unique needs of these groups.

“The cost of living with cancer is high – both in dollars and in collateral damage. As patients continue to share their stories through the Registry, the Cancer Support Community seeks to provide new hope strategies for moving the cancer community towards improving patient outcomes and reducing the cost of care,” said Kim Thiboldeaux, President and CEO of the Cancer Support Community.

The full 2014 Cancer Experience Registry Report, “Elevating the Patient Voice” is available online at [www.CancerSupportCommunity.org](http://www.CancerSupportCommunity.org). 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 Bristol-Myers Squibb, Celgene Corporation, Genentech, Inc., Janssen Biotech, Inc., Millennium: The Takeda Oncology Company, Onyx Pharmaceuticals, Inc., an Amgen Subsidiary, Pfizer Oncology and Pharmacyclics, Inc.

### **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 50 licensed Affiliates, more than 120 satellite locations and vibrant online and telephone communities, 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. Through cutting-edge psychosocial, behavioral and survivorship research, the Cancer Support Community’s Research and Training Institute is helping CSC change the future of cancer care through education and training. The Cancer Support Community’s Cancer Policy Institute ensures that the voices of 13.7 million cancer survivors and their families are heard in the nation’s capital and state and local legislatures across the country. In 2013, the CSC network delivered nearly \$48 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. For more information, please visit [www.CancerSupportCommunity.org](http://www.CancerSupportCommunity.org).

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