



**FOR IMMEDIATE RELEASE**

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## **CANCER RESEARCH MOVEMENT IDENTIFIES SOCIAL AND EMOTIONAL NEEDS OF PEOPLE LIVING WITH *MULTIPLE MYELOMA***

*Expanded Experience Registry created to identify social and emotional needs of people living with multiple myeloma*

**WASHINGTON - (June 27, 2013)** - The Cancer Support Community's Research and Training Institute has added a focus on people living with multiple myeloma to its nationwide Registry. According to the National Cancer Institute, there will be 22,350 new cases of multiple myeloma diagnosed in the U.S. this year. This type of blood cancer occurs most frequently in men and the risk of developing it increases with age. Also, multiple myeloma impacts African-Americans twice as much as other populations. The combinations of these demographics make it much more challenging to understand the entire physical, social and emotional spectrum of this disease.

Called the Cancer Experience Registry, the project has already collected the experiences of 4400 people who have volunteered to share their cancer journey by answering questions about their cancer experience. The new multiple myeloma component of the Registry is an effort to learn more about the specific social and emotional needs of this unique group.

To support the launch of this Registry, Onyx Pharmaceuticals joined as the inaugural sponsor of this specialized research endeavor in 2012. "The development of new therapies is making multiple myeloma an increasingly treatable cancer. As an organization on the forefront of innovation, Onyx is grounded by an enduring commitment to improve the lives of those with cancer," said Pablo Cagnoni, M.D., Executive Vice President, Global R&D and Technical Operations of Onyx Pharmaceuticals, Inc. "We are eager to learn more about the often-ignored social and emotional challenges that are specific to this group so that we can increase our knowledge and develop new solutions to address these needs."

Registry members who participate in the multiple myeloma portion of the Cancer Experience Registry will answer a series of questions about their experience including questions about the patient-medical team dialogue, side effect management, cancer care planning, financial effects, the ways in which they define value and the emotional and social effects of their cancer experience. Members will be able to instantly compare their responses with others in the community and get connected to support and resources that meet their interests and needs.

Cancer Experience Registry: Multiple Myeloma is the second Registry supported by Celgene Corporation, which joined as a sponsor in 2013. "Celgene is proud to be a partner in the Cancer Experience Registries. This program provides a unique opportunity to fully understand the

patient experience. As a company committed to delivering innovative solutions to patients, we believe the Registries are critical to enhancing the delivery of quality care and furthering comprehensive therapeutic solutions for patients living with multiple myeloma and metastatic breast cancer,” said Markus Renschler, MD, Corporate Vice President- Global Head of Hematology/Oncology Medical Affairs, Celgene Corporation.

In addition to the Cancer Experience Registry: Multiple Myeloma, the Cancer Support Community also has specific Registry initiatives for breast cancer and metastatic breast cancer. An annual index of findings from the Cancer Experience Registry, as well as each specialized community will be published to share the research with the cancer community at large.

“We are so pleased to be able to facilitate the transfer of this information from the voice of the patient to interventions that will impact direct clinical care” said Kim Thiboldeaux, President and CEO of the Cancer Support Community. “We are grateful to those who have selflessly shared their time and story with us and the broader cancer community, as we all strive to improve the experience of all people touched by cancer.”

The Cancer Support Community is pleased to have the Multiple Myeloma Research Foundation, the Leukemia and Lymphoma Society and the International Myeloma Foundation as generous contributors to and partners of the Cancer Experience Registry: Multiple Myeloma.

Those who have been diagnosed with multiple myeloma, or any type of cancer at any time are invited and encouraged to join the Registry by visiting [www.CancerExperienceRegistry.org](http://www.CancerExperienceRegistry.org).

### **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 2012, 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®. For more information, please visit <http://www.cancersupportcommunity.org>.

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