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HALF OF ALL PATIENTS WITH MULTIPLE MYELOMA DO NOT UNDERSTAND THE DISEASE AT DIAGNOSIS

The Cancer Support Community launches Frankly Speaking About Cancer: Multiple Myeloma

WASHINGTON - (September 13, 2013) - The Cancer Support Community (CSC) announced today the launch of *Frankly Speaking About Cancer: Multiple Myeloma* to address the educational needs of patients diagnosed and living with this rare form of blood cancer, as well as their caregivers. 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.

"The complexity of multiple myeloma creates additional challenges for patients and their families to understand the diagnosis and their treatment options," said Kim Thiboldeaux, President and CEO of the Cancer Support Community. "We are proud to partner with The Leukemia & Lymphoma Society to provide both educational materials and support services to address the needs of this population."

According to research done by CSC regarding the patient experience at diagnosis, over half (54%) of respondents reported that they did not understand their diagnosis at all. Almost half (44.3%) reported difficulty in obtaining information about their financial concerns; almost half (42.5%) reported difficulty finding resources for emotional support and one-third (31.4%) reported difficulty finding resources about how to work with their health care team to make treatment decisions.

In response to this need, CSC, in partnership with The Leukemia & Lymphoma Society has developed *Frankly Speaking About Cancer: Multiple Myeloma*. This program provides comprehensive information describing multiple myeloma, treatment options, tips and questions to help communication with health care team, resources for emotional support and a listing of resources to help individuals and families address the cost of cancer care.

Frankly Speaking About Cancer: Multiple Myeloma includes print and downloadable information, in-person workshops and online content. All materials are available free of charge by visiting www.cancersupportcommunity.org.

Patients are also encouraged to join the *Cancer Experience Registry: Multiple Myeloma* (www.cancerexperienceregistry.org) where they 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. Participants 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.

Frankly Speaking About Cancer: Multiple Myeloma was made possible thanks to the generous support of Millennium Pharmaceuticals, Novartis Oncology and Onyx Pharmaceuticals.

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 <u>www.cancersupportcommunity.org</u>.

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