

## FOR IMMEDIATE RELEASE

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## Patients with Multiple Myeloma Feel Unprepared to Make Treatment Decisions

Data presented at the American Society of Hematology Annual Meeting Reveals Gaps in Treatment Decision Support

SAN FRANCISCO – (Dec. 7, 2014) – Data presented by the Cancer Support Community's Research and Training Institute at the American Society of Hematology (ASH) annual meeting today shows that there remains a gap in patient readiness to make a treatment decision, even when provided with information.

A full 84 percent of patients participating in the Cancer Experience Registry: Multiple Myeloma reported being involved in making treatment decisions, yet only 40 percent felt prepared to discuss treatment options with their doctor, and 39 percent said they were not a bit prepared.

Furthermore, only 40 percent indicated that they received treatment decision support prior to therapy, and 25 percent said that they did not feel like they had a treatment choice. On a positive note, the study also indicated that patients who prepared a list of their questions and concerns about treatment prior to their medical consultation felt significantly more prepared to make decisions than those who did not.

"With advancements in treatment, people with multiple myeloma are living longer, fuller lives. However, with these advancements, patients must now make complex treatment choices," said Kim Thiboldeaux, president and CEO of the Cancer Support Community. "In addition to providing information to patients, we must ensure they have the skills to utilize the information and resources in a way that fully prepares them for these complex decisions."

The full poster can be accessed here.

This research underscores the need for additional efforts to address gaps in treatment decision making preparedness, which may include treatment decision counseling for people with cancer.

The data was collected from 280 patients with multiple myeloma in the <u>Cancer Experience Registry</u>, a research initiative with the goal of collecting, analyzing and sharing information about the experience and needs of patients and their families throughout the cancer journey. The Cancer Experience Registry currently has more than 7,000 members, and nearly 500 are part of the Cancer Experience Registry: Multiple Myeloma.

The Cancer Experience Registry: Multiple Myeloma is made possible thanks to support from Onyx Pharmaceuticals, Inc., an Amgen subsidiary, and Celgene Corporation.

## **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

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