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Patient Experience with Chronic Lymphocytic Leukemia Not Widely Discussed

Cancer Support Community Tackles the CLL Experience in New Cancer Experience Registry

WASHINGTON - (May 26, 2015) - The Cancer Support Community (CSC), an international nonprofit dedicated to providing support, education and hope to people impacted by cancer, announced today a new Registry specifically for people with chronic lymphocytic leukemia (CLL). This addition to CSC's Cancer Experience Registry will explore details regarding the treatment, management and perceptions surrounding a cancer that will impact over 106,000 people in the U.S. this year.

"We are pleased the reach of the Cancer Experience Registry is expanding," said Kim Thiboldeaux, CEO of the Cancer Support Community. "The data gathered from this new Registry will shed light on the full impact of CLL, while providing a support network for people living with this disease."

"We're proud to sponsor the development of this Registry and applaud CSC for this initiative," said Cindy Guzzo, Vice President of Medical Affairs at Janssen Biotech. "While CLL is one of the most common blood cancers, it is still considered a rare disease, which means the information gathered in the Registry is extremely important."

The Cancer Support Community introduced the Cancer Experience Registry as a way to give a voice to people living with cancer and to convey the specific emotional, financial and social impacts of living with cancer to the cancer community at large. The CLL Registry is the ninth in a series of specialty Registries reaching into specific cancer types. In addition to the Cancer Experience Registry which is open to anyone with any type of cancer, there are Registries for patients with breast cancer, metastatic breast cancer, multiple myeloma, chronic myeloid leukemia, lung cancer and melanoma. Caregivers are also invited to participate by joining the Cancer Experience Registry: Caregivers and Multiple Myeloma Caregivers.

"Registries provide important information about the natural history of a disease and help clinicians better understand how to appropriately treat patients," said Elizabeth Faust, Ph.D., Head of Medical Affairs at Pharmacyclics. "We believe that the insights gathered from this CLL-focused Registry will enhance CLL treatment."

The Cancer Experience Registry: Chronic Lymphocytic Leukemia is made possible thanks to a generous sponsorship from Janssen Biotech, Inc. and Pharmacyclics.

For more information on the Cancer Experience Registry: CLL and Cancer Experience Registry: Caregivers, please visit 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 more than 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 2014, the CSC network delivered nearly \$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 www.CancerSupportCommunity.org

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