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Linda House
317-997-0561

Linda@cancersupportcommunity.org

Andrea Greif
914-821-8958

Andrea.greif@lls.org

CHRONIC MYELOID LEUKEMIA: PATIENT EXPERIENCE NOT WELL UNDERSTOOD

*The Cancer Support Community and The Leukemia & Lymphoma Society
partner on a solution*

WASHINGTON - (October 24, 2013) - The Cancer Support Community's Research and Training Institute and The Leukemia & Lymphoma Society (LLS) have joined forces to launch the Cancer Experience Registry: Chronic Myeloid Leukemia. According to LLS's Facts 2013 booklet, there will be 5,920 new cases of chronic myeloid leukemia (CML) diagnosed in the U.S. this year, making it a rare form of cancer. However, thanks to groundbreaking research advances, supported in part by LLS funding, there are now several effective therapies to treat patients with CML, and a growing number of people are living with the disease.

"CML patients are living longer, fuller lives due to treatment advances, but we believe that survivorship comes with an array of physical and psychosocial issues. Patients will tell us more about these issues and their impact through the Cancer Experience Registry," said Louis DeGennaro, Ph.D., LLS's chief mission officer.

Called the Cancer Experience Registry, the global project has already collected information on approximately 5200 people who have volunteered to share their cancer journey by answering questions about their experiences. The new CML component of the registry is an effort to learn more about the specific social and emotional needs of this unique group.

"We are excited about partnering with the Cancer Support Community on this important project," said Clare Karten, senior director, patient engagement for LLS. "Joining forces adds to our understanding about patients' experiences and gives us the opportunity to work together with patients to affect change that will improve their quality of life."

According to Joanne Buzaglo, Ph.D., vice president, research and training for the Cancer Support Community, "The partnership between LLS and CSC truly allows us to combine the expertise and reach of each organization, enabling us to apply learning from the registry to solutions that are meaningful for patients and their families."

Patients who participate in the Cancer Experience Registry: Chronic Myeloid Leukemia will answer a series of questions about their experiences including questions about the patient-medical team dialogue, side effect management, cancer care planning, financial concerns and the emotional and social effects of their cancer experiences. Participants will be able to instantly compare their responses with those of others in the community and get connected to support and resources that meet their interests and needs.

This fourth in a series of cancer specific registries is possible thanks to the generous support of Pfizer Oncology, the Inaugural Sponsor. "Learning the patient's perspective is critically important," said Mace Rothenberg, MD, senior vice president, clinical development and medical affairs, Pfizer Oncology. "We are pleased to partner with the Cancer Support Community and LLS on this initiative."

In addition to people with a diagnosis of Chronic Myeloid Leukemia, the Cancer Support Community encourages all patients touched by any cancer to join the broader Cancer Experience Registry to lend their voice and be connected to additional resources. An annual index of findings from the Cancer Experience Registry, as well as results from each cancer specific registry, 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 stories with us and the broader cancer community, as we all strive to improve the experience of all people touched by cancer."

Those who have been diagnosed with chronic myeloid leukemia or any type of cancer at any time are invited and encouraged to join the registry by visiting www.CancerExperienceRegistry.org or by calling 1-888-793-9355 to request a paper copy of the survey.

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 www.cancersupportcommunity.org.

About The Leukemia & Lymphoma Society

The Leukemia & Lymphoma Society® (LLS) is the world's largest voluntary health agency dedicated to blood cancer. The LLS mission: Cure leukemia, lymphoma, Hodgkin's disease and

myeloma, and improve the quality of life of patients and their families. LLS funds lifesaving blood cancer research around the world, provides free information and support services, and is the voice for all blood cancer patients seeking access to quality, affordable, coordinated care.

Founded in 1949 and headquartered in White Plains, NY, LLS has chapters throughout the United States and Canada. To learn more, visit www.LLS.org. Patients should contact the Information Resource Center at (800) 955-4572, Monday through Friday, 9 a.m. to 6 p.m. ET.

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