

## FOR IMMEDIATE RELEASE

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## SOCIAL AND EMOTIONAL NEEDS OF PEOPLE IMPACTED BY LUNG CANCER MASKED BY STIGMA

Cancer Support Community Launches Cancer Experience Registry: Lung Cancer

WASHINGTON – (Feb. 24, 2015) – The Cancer Support Community (CSC), an international nonprofit dedicated to providing support, education and hope to people impacted by cancer, launched today a new registry for people impacted by lung cancer. This project will measure the social, emotional and financial impact on people with this diagnosis, which, according to the National Cancer Institute, accounts for 13.5 percent of all cancer diagnoses in the United States.

The Cancer Experience Registry: Lung Cancer is an expansion of CSC's broader Cancer Experience Registry, a first-of-its-kind study dedicated to fully understanding the experiences of people living with cancer. Since its launch, the Cancer Experience Registry has collected over a million data points from more than 7,600 people who have ever been diagnosed with cancer. This new registry will provide a better understanding of the social and emotional needs of people diagnosed with lung cancer.

"A diagnosis of lung cancer can create a unique set of challenges. The Cancer Experience Registry: Lung Cancer will allow patients to help us understand these challenges and enable the broader community to create patient-centered solutions for the future," said Gwen Darien, executive vice president of programs and services at the Cancer Support Community.

Participants in the Cancer Experience Registry: Lung Cancer will answer a series of questions about their experiences, including questions about the psychosocial impact of lung cancer and its stigma, their understanding of available treatment options and the financial impact of the disease, among other topics. Members will be able to instantly compare their responses to the questions in the survey with others in the community, get connected to support and resources that meet their unique needs and have the option to receive additional information from CSC and its partners.

"At Bristol-Myers Squibb, we take a comprehensive view of the patient journey from diagnosis through follow up care," said Joseph Leveque, MD, vice president, Oncology, U.S. Medical, Bristol-Myers Squibb. "For lung cancer patients, we are committed to provide support and education during their times of need, and we believe the registry will provide valuable insights that can be used to better address the needs and challenges facing this community."

"From the Registry I learned I am not alone - in my anxiety or sadness - of living with stage 4 cancer," said Ide Mills, Cancer Experience Registry member and Cancer Experience Registry: Lung Cancer Advisory Council member. "Our voice, the patient voice, through the Registry is elevated - because together we bring credibility to our evolving experiences."

"Lilly Oncology is excited to further our partnership with the Cancer Support Community and the expansion of their patient registry," said Newt Crenshaw, vice president, U.S. and Canada business unit leader, Lilly Oncology. "Supporting the lung cancer registry aligns to our efforts to better understand the journeys of cancer patients and to better develop solutions to address their needs."

CSC would like to thank our partners in developing the Cancer Experience Registry: Lung Cancer: LUNGevity Foundation, American Lung Association, Lung Cancer Alliance and Free to Breathe.

For more information on the Cancer Experience Registry: Lung Cancer, please visit <a href="https://www.CancerExperienceRegistry.org">www.CancerExperienceRegistry.org</a>.

The Cancer Experience Registry: Lung Cancer was made possible thanks to support from Bristol-Myers Squibb and Lilly Oncology.

## **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 \$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. So that no one faces cancer alone®. For more information, please visit <a href="https://www.CancerSupportCommunity.org">www.CancerSupportCommunity.org</a>