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UNDERSTANDING THE IMPACT OF CANCER ON CAREGIVERS

Cancer Support Community launches Cancer Experience Registry: Caregivers

WASHINGTON – (Feb. 10, 2015) – The Cancer Support Community (CSC), an international cancer nonprofit, launched today a research initiative to measure the social, emotional and financial impact of cancer on caregivers.

The project, Cancer Experience Registry: Caregivers, is an expansion of CSC's Cancer Experience Registry, which, since its launch, has collected over a million data points on more than 7,500 people who have had cancer. Similar to this patient registry, the new Cancer Experience Registry: Caregivers will ask caregivers a series of questions about their experience and will connect them to a network of support.

"For decades we have known that cancer impacts not just the people who are diagnosed, but those caring for and about them as well," said Kim Thiboldeaux, CEO of the Cancer Support Community. "The registry for caregivers will help identify the unique challenges of this community and create better resources to address their needs."

The Cancer Support Community defines a caregiver as anyone who provides physical, emotional, spiritual, financial or logistical support to a loved one with cancer. This could include family members, co-workers, friends or neighbors. Anyone who self-identifies as a caregiver of someone with cancer, whether currently or in the past, is eligible to join the registry at <u>www.CancerExperienceRegistry.org</u>.

"Onyx Pharmaceuticals supports the continued development of the Cancer Experience Registry to gather critical information on the unique needs of caregivers," said Pablo J. Cagnoni, M.D., President, Onyx Pharmaceuticals, Inc., an Amgen subsidiary. "We believe this innovative program has great potential to provide insights that may improve the lives of those impacted by cancer."

As a part of sharing their experiences as caregivers, participants in the Cancer Experience Registry: Caregivers will be able to immediately compare their responses to survey items with others and will have the option to participate as a part of the community.

"The Cancer Experience Registry: Caregivers is more than just a research project — it is also a community where people can listen to the stories of others and find professional and peer support when they need it," said Joanne Buzaglo, Ph.D., Senior Vice President of Research & Training at the Cancer Support Community.

"We are proud to support the Cancer Experience Registry: Caregivers and believe that providing support, both practical and emotional, for caregivers is imperative in an effort to connect people, information and resources. It is just one way we are striving to help improve patient care as we understand support beyond medicine," said Dawn Justus, RN, Lilly Oncology Brand Director. In developing the Cancer Experience Registry: Caregivers, the Cancer Support Community is joined by advocacy partners Leukemia & Lymphoma Society, National Alliance for Caregiving, Rosalynn Carter Institute for Caregiving, C-Change and the American Cancer Society.

The Cancer Experience Registry: Caregivers was created thanks to support from its inaugural sponsor, Onyx Pharmaceuticals, an Amgen subsidiary, and Lilly Oncology.

For more information, 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 \$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 www.CancerSupportCommunity.org