

CANCER SUPPORT COMMUNITY SUPPORTS THE "PATIENT EXPERIENCE IN RESEARCH ACT OF 2017" (H.R. 2244) TO IMPROVE CLINICAL TRIALS

CSC applauds Rep. Leonard Lance and Rep. Diana DeGette for introducing patient-focused legislation

WASHINGTON – (May 2, 2017) – The Cancer Support Community (CSC), an international nonprofit organization, announces its support for the bipartisan legislation, H.R. 2244, introduced by Rep. Leonard Lance (R-NJ) and Rep. Diana DeGette (D-CO) in the U.S. House of Representatives. CSC commends Congressman Lance and Congresswoman DeGette for their continued leadership and advocacy on patient protection and patient-centered legislation.

The "Patient Experience in Research Act of 2017" (PERA) will launch a voluntary pilot project to evaluate the social and emotional distress experienced by patients participating in a clinical trial of a drug or biological product that is intended to treat a serious or life-threatening disease or condition.

There is general agreement in the medical community that clinical trials are the best way to learn what works in treating diseases like cancer. For cancer patients, clinical trials provide them access to new cutting-edge therapies, often the next generation of treatment. This can be a new drug, a combination of drugs, or a different way of using established therapies.

However, according to CSC's *Access to Care in Cancer 2016: Barriers and Challenges* report, over 53 percent of surveyed cancer patients did not receive social and emotional support services, including screening for distress as part of their cancer care. Psychosocial distress screening and support is a fundamental element of comprehensive cancer care.

"CSC applauds the vision and leadership to introduce this transformative bill," said Kim Thiboldeaux, CEO of the Cancer Support Community. "Integrating the collection of information about the patient experience into clinical research will ensure that valuable information is shared in a new and meaningful way. As a result, we expect that in the future, doctors will be able to identify patient needs early on and intervene as appropriate, thus making sure that the patient adheres to the recommended treatment protocol in order to achieve the best possible outcome and quality of life."

"A difficult diagnosis can take its toll on a patient. Information about the patient experience, including the challenges that come with a diagnosis, is needed to help improve the clinical trial process. Many patients are counting on the research and the products that are being developed in promising clinical trials. I am proud to introduce this bipartisan bill with my colleague

Representative DeGette to help measure additional factors so patients and their caregivers have the best research," said Lance, a member of the Energy and Commerce Health Subcommittee.

"I'm pleased to introduce the [PERA] with Congressman Lance," DeGette said. "Like all patients, people participating in clinical trials often experience psychological distress related to their conditions. [PERA] will help ensure that patients stay with clinical trials by testing ways to offer support to those who need it. Robust clinical trial participation is essential to advancing biomedical research. By closing current gaps in care for patients taking part in trials, we can both improve health outcomes and enhance the clinical trial itself."

In 2013, Lance was honored by CSC's Cancer Policy Institute with the Public Policy Award for Research for his commitment to health and cancer care issues. DeGette was one of the two original authors of the bipartisan 21st Century Cures Act, which allocated \$1.8 billion in cancer research funding when it became law in December. CSC is committed to working with members of Congress to build strong bipartisan support for PERA in order to protect cancer patients and their loved ones nationwide.

About the Cancer Support Community

As the largest professionally led nonprofit network of cancer support worldwide, the Cancer Support Community (CSC) is dedicated to ensuring that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community. CSC achieves its mission through three areas: direct service delivery, research, and advocacy. The organization includes an international network of Affiliates that offer the highest quality social and emotional support for people impacted by cancer, as well as a community of support available online and over the phone. The Research and Training Institute conducts cutting-edge psychosocial, behavioral, and survivorship research. CSC furthers its focus on patient advocacy through its Cancer Policy Institute, informing public policy in Washington, D.C. and across the nation. In 2016, the CSC network delivered nearly \$45 million in free services to patients and families. For more information, please call the toll-free Cancer Support Helpline at 888-793-9355, or visit www.CancerSupportCommunity.org. *So that no one faces cancer alone*®

###