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Lung Cancer Patients to Help Medical Community Understand the Side Effects of Immunotherapy Treatment

*Study designed to help doctors better understand and educate patients with non-small cell lung cancer on what to expect when undergoing immunotherapy treatment.*

SAN CARLOS, Calif. (January 18, 2018) — The Lung Cancer Registry sponsored by the Bonnie J. Addario Lung Cancer Foundation (ALCF), the American Lung Association’s LUNG FORCE and the International Association for the Study of Lung Cancer (IASLC), is joining Adam Dicker, M.D., Ph.D. at Sidney Kimmel Cancer Center, Thomas Jefferson University and Heather Jim, Ph.D. at H. Lee Moffitt Cancer Center and Research Institute, Inc., in a study to learn about side effects of immunotherapy from patients with non-small cell lung cancer (NSCLC) who have undergone therapy with immune checkpoint inhibitors. In addition, the Society for Immunotherapy of Cancer (SITC) will join the collaboration as a project partner to maximize awareness of the registry and this research study to both researchers and patients.

Immune checkpoint inhibitors, a form of immunotherapy, have been shown to bring about durable remissions and prolonged survival for patients with NSCLC, but at the cost of toxicity that causes a range of side effects. The goal of this study is to gather information directly from patients and caregivers to better understand what side effects patients have experienced, when side effect symptoms began and how side effects have impacted the patients’ quality of life. Results from the study will give doctors a greater understanding of the how immune checkpoint inhibitor toxicities affect patients and allow them to better inform patients considering immunotherapy treatment for NSCLC.
“Nearly a quarter million Americans will be diagnosed with lung cancer this year,” said Bonnie J. Addario, 14-year lung cancer survivor and founder of the ALCF. “Immunotherapy, along with targeted therapy, has helped transform the treatment of lung cancer over the past decade. Gathering information from patients and passing that knowledge on to other lung cancer patients accurately and quickly is helping patients live longer, which is our goal.”

The study represents the first collaborative effort since the ALCF and the Lung Association joined forces with the IASLC in December 2017 to expand the Lung Cancer Patient Registry. The registry allows patients to contribute information that improves understanding of lung cancer treatments and enables researchers to use that information to improve patient care and outcomes.

“We’re inspired by the opportunity to put the Lung Cancer Patient Registry to innovative use,” said Harold P. Wimmer, National President and CEO of the American Lung Association. “The patient-provided data used in this new trial will allow us to gain knowledge from patients directly and better inform treatment.”

“Patient-reported outcomes (PRO’s) can help show clinical benefit in reducing disease related symptoms, provide more accurate estimates of toxicity, help model treatment costs and improve symptom management,” said Adam P. Dicker, M.D., PhD, Sidney Kimmel Cancer Center, Thomas Jefferson University, Philadelphia, PA. “These toxicities really do have costs, and it’s important for patients to know how much out-of-pocket costs they might incur.”

Lung cancer is the leading cause of cancer-related deaths in the U.S., accounting for one in four cancer deaths each year. The goal behind creating the registry is to speed and improve research by collecting information scientists can use in developing new treatments. In addition, the registry builds a bridge between patients and clinical trials’ researchers by enabling researchers to submit proposals to enter clinical trials into a database that patients can search.

“When all involved in lung cancer collaborate, patient outcomes improve,” said IASLC CEO Fred R. Hirsch, MD, PhD. “Information gathered in the study will be available to patients, their physicians, caregivers and to researchers evaluating the effectiveness of different treatment options.”

Patients with any form or stage of lung cancer, including patients with NSCLC who are interested in participating in the immunotherapy research study, can join the registry at www.lungcancerregistry.org. There, patients can opt-in to contribute their information, set their contact preferences and compare their experience with lung cancer with others. Patients can choose to receive information about research opportunities or other relevant news as part of their participation.

About the Bonnie J. Addario Lung Cancer Foundation
The Bonnie J. Addario Lung Cancer Foundation (ALCF) is one of the largest philanthropies (patient-founded, patient-focused, and patient-driven) devoted exclusively to eradicating lung cancer through research, early detection, education, and treatment. The foundation’s goal is to work with a diverse group of physicians, organizations, industry partners, individuals, patients, survivors, and their families to identify solutions and make timely and meaningful change and turn lung cancer into a chronically managed disease by 2023. The ALCF was established on March 1, 2006 as a 501c(3) nonprofit organization and has raised over $30 million for lung cancer research and related programs. The foundation has received four stars from Charity Navigator and has earned the platinum GuideStar nonprofit seal of transparency. Follow us on Twitter @thealcf.

About the American Lung Association
The American Lung Association is the leading organization working to save lives by improving lung health and preventing lung disease, through research, education and advocacy. The work of the American Lung Association is focused on four strategic imperatives: to defeat lung cancer; to improve the air we breathe; to reduce the burden of lung disease on individuals and their families; and to eliminate tobacco use and tobacco-related diseases. For more information about the American Lung Association, a holder of the Better Business Bureau Wise Giving Guide Seal, or to support the work it does, call 1-800-LUNGUSA (1-800-586-4872) or visit: Lung.org.

About International Association for the Study of Lung Cancer
The International Association for the Study of Lung Cancer (IASLC) is the only global organization dedicated to the study of lung cancer. Founded in 1974, the association's membership includes more than 6,500 lung cancer specialists in over 100 countries. IASLC members work to enhance the understanding of lung cancer among scientists, members of the medical community and the public. IASLC publishes the Journal of Thoracic Oncology, a valuable resource for medical specialists and scientists who focus on the detection, prevention, diagnosis and treatment of lung cancer. Visit www.iaslc.org for more information and follow us on Twitter @IASLC.

About the Society for Immunotherapy of Cancer
The Society for Immunotherapy of Cancer (SITC) is the world's leading member-driven organization specifically dedicated to improving cancer patient outcomes by advancing the science and application of cancer immunotherapy. Established in 1984, SITC, a 501(c)(3) not-for-profit organization, serves scientists, clinicians, academicians, patients, patient advocates, government representatives and industry leaders from around the world. Through in-person and online educational programs that provide state-of-the-art continuing education for the entire cancer care team; open access peer-reviewed guidelines, articles and other resources; interactive, audience-specific online communities; and by fostering collaboration between expert researchers and oncology practitioners, SITC aims to one day make the word "cure" a reality for cancer patients everywhere.