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The Bonnie J. Addario Lung Cancer Foundation, the American Lung Association and the International Association for the Study of Lung Cancer Collaborate to Find a Cure for the World’s Deadliest Cancer

The newly expanded Lung Cancer Patient Registry provides additional tools for lung cancer patients and researchers

SAN CARLOS, Calif. (January 10, 2018) — The Bonnie J. Addario Lung Cancer Foundation (ALCF) and the American Lung Association’s LUNG FORCE welcome the International Association for the Study of Lung Cancer (IASLC) as a new member of the Lung Cancer Patient Registry, a place to gather and store detailed patient information, providing a real world view of patient outcomes and treatment effectiveness. Lung cancer patients enter information anonymously into the Registry. Registered patients, their families, health care providers and researchers can access that information.

“Nearly a quarter million Americans will be diagnosed with lung cancer this year, and the Registry is the first of its kind, patient-driven resource where patients share their information about living with lung cancer to allow scientists and researchers the opportunity to learn from patients firsthand,” said Bonnie J. Addario, 14-year lung cancer survivor and founder of the ALCF.

The Registry includes the ability for registered researchers to query de-identified data in any combination of data elements using the research portal online search tool. Researchers interested in submitting proposals for placing clinical trials within the Registry may now submit a proposal.

“Anytime patients and doctors can collaborate more effectively, we improve the experience for both,” said Fred R. Hirsch, CEO of the IASLC. “As a global, multidisciplinary organization with a mission to conquer lung cancer, we look forward to the collaboration and the impact of the Lung Cancer Registry and are thrilled to join the partnership.”

This month, the Lung Cancer Registry will launch a study on the side effects of immunotherapy on non-small cell lung cancer (NSCLC) patients using data provided by patient participants. There is increasing awareness of the importance of collecting patient reported outcomes in oncology, especially long-term survivors whose toxicity is generally not reported in clinical trials. The findings will help educate other
NSCLC patients and their families about side effects that are likely to occur and how they will affect the patients’ quality of life.

“Lung Cancer is a complex disease which requires a multi-pronged attack,” said Harold Wimmer, National President and CEO of the American Lung Association. “Continuing our collaboration with the Bonnie J. Addario Foundation, and joining forces with the International Association for the Study of Lung Cancer in support of the Lung Cancer Registry, will allow us to collectively have an even greater influence on lung cancer research and awareness.”

Patients with any form or stage of lung cancer can join the Registry at www.lungcancerregistry.org. Patients can opt-in to contribute their information, set their contact preferences and compare their lung cancer experience with others in The Registry. 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) non-profit organization and has raised over $30 million for lung cancer research and related programs. 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.