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Bonnie J. Addario Lung Cancer Foundation and ALK-Positive Patient Group Partner to Encourage Members to Join Lung Cancer Registry

SAN CARLOS, Calif. (September 20, 2018) – The Bonnie J. Addario Lung Cancer Foundation (ALCF) is partnering with ALK Positive, an online community of over 1,200 members worldwide dealing with ALK-positive lung cancer, to encourage Lung Cancer Registry membership. ALCF, along with partners, the American Lung Association’s LUNG FORCE and the International Association for the Study of Lung Cancer (IASLC), developed the Lung Cancer Registry to provide researchers and clinicians with a data repository of information on all types of lung cancer, including ALK-positive lung cancer patients, as well as other genetic subpopulations, that they can use to further research.

“The cure for cancer lies within the patient” said Bonnie J. Addario, 14 year lung cancer survivor and founder of ALCF. “The work that the ALK Positive lung cancer group is doing to advance research for this oncogene, and all lung cancer patients, is critical to creating a paradigm shift. Nearly a quarter million Americans will be diagnosed with lung cancer this year, and this patient-driven resource where patients share their information about living with lung cancer allows scientists and researchers the opportunity to learn from patients first hand.”

ALK-positive lung cancer is rare, representing only 4 to 7 percent of non-small cell lung cancer cases. Because the number of patients who have this form of lung cancer is relatively small, doctors and researchers have a hard time gathering information about the disease and treatments from the patient perspective. The registry provides a critical path to information about this important subpopulation.

“The Lung Cancer Registry is a game changer,” said Tom Carroll, who co-founded ALK Positive with his wife, Merita, before she died from lung cancer in April 2018. “The registry links patients and their data
to doctors and researchers searching for better treatments. We strongly believe patient data provides
the key to solving the puzzle of ALK-positive lung cancer. The more patients who take part in the
registry, the faster we can move towards a cure.”

ALCF and ALK Positive have partnered to create awareness of and increase participation in ALK-positive
lung cancer research - ultimately to advance treatment of the disease. With participation in the
registry, patients gain access to aggregated data gathered from the community and can learn about the
experiences of other lung cancer patients. Additionally ALCF has provided a registry resource guide for
ALK members to reference in community outreach and fundraising. The guide also answers patient and
caregiver questions about privacy, including how the organizations will use the collected information.

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**About ALK Positive**

ALK Positive is an online community where non-small cell lung cancer (NSCLC) patients and caregivers
afflicted with the anaplastic lymphoma kinase (ALK) gene mutation/rearrangement can join with like
patients to share support, empathy, and information. NSCLC ALK Positive patients make up only about
five percent of all lung cancer diagnoses each year. Since its founding as a Facebook support group in
2015, ALK Positive has grown to 1,200 members worldwide. For more information about ALK Positive
please visit [www.alkpositive.org](http://www.alkpositive.org) or follow us on [Facebook](https://www.facebook.com) or [Twitter](https://twitter.com).

**About the Bonnie J. Addario Lung Cancer Foundation**

The Bonnie J. Addario Lung Cancer Foundation (ALCF) is one of the largest international 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. The ALCF was established on March 1, 2006, as a 501c(3) nonprofit
organization and has raised more than $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. For more information about ALCF please visit
[www.lungcancerfoundation.org](http://www.lungcancerfoundation.org) or follow us on [Facebook](https://www.facebook.com) or [Twitter](https://twitter.com).

**About the 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](http://www.iaslc.org) for more information and follow us on Twitter @IASLC.
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.