



Contact:

Lisa Rivero

Vice President

lrivero@jpa.com | +1 617-657-1305

Becky Bunn, MSc

Public Relations Manager

Becky.Bunn@IASLC.org | +1 720-254-9509

Oncogene-Driven Patient-Caregiver Communities Creating New Paradigm for Non-Small Cell Lung Cancer Research

Toronto, Canada – September 23, 2018 – A recent review of patient-caregiver communities focused on non-small cell lung cancer (NSCLC) with genomic alterations show that these groups are improving outcomes by supporting patients and caregivers, increasing awareness and education and accelerating research. Today, patient advocate Janet Freeman-Daily, co-founder of the community known as [The ROS1ders](#), Robert C. Doebele, M.D., Ph.D. of the Division of Medical Oncology at the University of Colorado, and Christine M. Lovly, M.D., Ph.D. of the Vanderbilt University School of Medicine, presented these findings at the International Association for the Study of Lung Cancer's (IASLC's) 19th World Conference on Lung Cancer (WCLC) in Toronto, Canada.

"These oncogene-driven groups created by patients and caregivers are ushering in a new era for lung cancer research partnerships," said Freeman-Daily. "By collaborating with researchers, clinicians, advocacy groups and industry, we are accelerating research into our own diseases."

Genomic alterations drive more than 60 percent of NSCLC. Approximately 20 percent of NSCLC cases have an oncogenic driver, such as EGFR, ALK, ROS1 or BRAF, that physicians can treat with approved, targeted drugs and clinical trials. The communities, formed by patients and caregivers dealing with cancers driven by these oncogenes, use a variety of tools for education and support including Facebook groups, websites, newsletters, social media and blogs, and provide information about treatments, common experiences, tips from clinicians and real-life connections.

The growth of these groups is impressive:

- [ALK Positive](#) focuses on ALK+ lung cancer and has more than 1,200 members from more than 40 countries.
- [Exon 20 Group](#) focuses on EGFR and HER2 Exon 20 insertions and has 243 members from 22 countries.
- [The ROS1ders](#) focus on ROS+ cancer of all types and has 323 members from 22 countries across eight cancer types.
- [EGFR Resisters](#) focuses on EGFR+ NSCLC as well as cancers that develop resistance to EGFR-targeted therapies and has more than 650 members from 24 countries.
- RET Renegades, which formed only a few months ago, has 43 members from two countries.

"It is an honor to work with this team of amazing lung cancer patients, advocates and scientists," said Dr. Lovly, who works with the ROS1ders. "Patient-partnered research is critical to build better treatments for and bring hope to all lung cancer patients."

These groups accelerate research in many ways including:

- ALK Positive partnered with [LUNGeivity Foundation](#) to award three NSCLC grants totaling \$600,000 in May 2018.
- Exon 20 Group partnered with [International Cancer Advocacy Network](#) to assist patients in identifying and enrolling in clinical trials and fund research.
- The ROS1ders collaborated with the [Bonnie J. Addario Lung Cancer Foundation](#) and its sister foundation, the [Addario Lung Cancer Medical Institute](#), to develop and fund two arms of the ROS1 Cancer Model Project. This project aims to create new ROS1 cell lines and patient-derived xenograft (PDX) mouse models from tissue and fluid donations collected from ROS1ders during medically necessary procedures. In early 2017, only a few ROS1 cell lines and one ROS1 PDX model existed. Today, Freeman-Daily announced two ROS1 PDX models are in development and researchers have created four new ROS1 cell lines that researchers will broadly distribute.

“The oncogene-driven patient groups are positioned to make a huge difference in these rare lung cancers,” said Dr. Doebele. “For ROS1+ cancers, the ROS1 Cancer Model Project is essential for supporting ongoing research into the biology, testing and drug development for the disease.”

About WCLC

The World Conference on Lung Cancer (WCLC) is the world’s largest meeting dedicated solely to lung cancer and other thoracic malignancies, attracting over 7,000 researchers, physicians and specialists from more than 100 countries. The conference will cover a wide range of disciplines and unveil research studies and clinical trial results. For more information, visit <http://wclc2018.iaslc.org/>. Follow the conference on social media with: #WCLC2018.

About IASLC

The International Association for the Study of Lung Cancer (IASLC) is the only global organization dedicated solely to the study of lung cancer and other thoracic malignancies. Founded in 1974, the association's membership includes more than 7,500 lung cancer specialists across all disciplines in over 100 countries, forming a global network working together to conquer lung and thoracic cancers worldwide. The association also publishes the *Journal of Thoracic Oncology*, the primary educational and informational publication for topics relevant to the prevention, detection, diagnosis and treatment of all thoracic malignancies. Visit www.iaslc.org for more information. You can also follow the IASLC on [Twitter](#), [Facebook](#), [LinkedIn](#) and [Instagram](#).

###