

ALK POSITIVE

ALK POSITIVE SUPPORT

✓Origins & History

In 2015, Merita and Tom Carroll started a Facebook support group for patients/survivors and caregivers to share information, empathy, and support.

Today, ALK Positive is a patient-driven support group dedicated to advancing research and advocacy to change the future of ALK-positive lung cancer.

In 2017, ALK Positive Outreach was formed to improve the life expectancy and quality of life for ALK-positive lung cancer patients worldwide. Within its first year, ALK Positive Outreach initiated four internal programs to help ALK Positive members:

- **The Second Opinion Program.** To assist members with obtaining a second opinion from the top known ALK-positive lung cancer oncologists/specialists in the world.
- **The Oncologist Directory.** To inform members of known ALK-positive lung cancer experts worldwide.
- **The Clinical Trial Database.** To direct members to all trials accepting ALK-positive lung cancer patients.
- **The ALK Positive Members Map.** To connect members together based on geographic location, enhancing relationships and member support.

✓Patient Demographics

The average age for ALK Positive patients is about 50 years.

Well over 80% of ALK Positive patients are diagnosed stage 4 NSCLC Adenocarcinoma.

About 60% of ALK Positive patients are female.

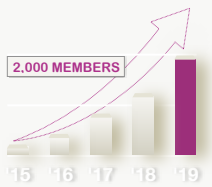
Among members, about 65% of patients have never smoked or were former smokers.

Within ALK Positive, 70% are patients and 30% comprise caregivers, family, and friends.



✓ALK Positive Mission

By the end of 2019, there will be close to 2,000 ALK Positive members across 5 continents in over 42 countries. ALK Positive has the mission to improve the life expectancy and quality of life for ALK-positive lung cancer patients worldwide.



ALK POSITIVE ADVOCACY

✓ALK Positive Outreach

In July 2017, a core group of ALK Positive members agreed to brainstorm on raising money for research. LUNGevity embraced our vision and agreed to cover ALK Positive under their 501(c)3 status. By May 2018, ALK Positive Outreach formulated bylaws, elected officers, and established the following teams to support our overall mission of improving the life expectancy and quality of life of ALK-positive lung cancer patients: Executive Board; Medical & Pharmaceutical Advocacy Committee; Media, Alliance & Membership Committee; Political Advocacy Committee; Fundraising Committee; and the Finance Committee.

✓Collaborations & Partnerships

The core of ALK Positive is providing information, empathy, and support to members. The core of ALK Positive Outreach is research, advocacy, and partnerships which aim to save lives. The following collaborations are currently in progress:



- **Lung Cancer Registry.** To build a repository of lung cancer data for scientists and researchers with over 500 ALK Positive member participants.
- **SPACEWALK Study.** To determine causes of ALK TKI resistance. Free NGS for patients. The target is 300 ALK samples.
- **Broad Institute & Pattern.org.** To donate member biopsy tissue to develop cell lines and organelles of ALK-positive cancer cells for researchers. Launching for ALK Positive members in 2019.
- **National Lung Cancer Roundtable.** To develop action plans within focus groups addressing screening, lung cancer in women, and other key advocacy efforts.
- **Oncogene Collaborative Initiative.** To align key partners to enhance the diagnostic accuracy and clinical management of lung cancer patients; a Biden Cancer Initiative partnership.

ALK Positive Outreach has been working with LUNGevity, Go2 Foundation, ALCMI, ACS, NLCRT, IASLC, LUNGCAN, NCCN, Guardant 360, Foundation One Medicine and other lung cancer oncogene groups, to name a few.

✓Partner with Us

Partner with us in advancing research and advocacy. ALK Positive can offer alliance partners patient member data from surveys, blood samples, and tissue samples in order to enhance research. Partner with ALK Positive in any way possible to improve outcomes for ALK-positive patients worldwide. How can you help more ALK-positive patients receive the best available diagnosis and treatments? Visit www.alkpositive.org to contact us and learn more.

ALK POSITIVE RESEARCH

✓2017-2019 LUNGevity = \$700,000

The ALK Positive Research Fund was established in 2017. In 2018, three (3) \$200,000 "translational research" grants were awarded with the aim of improving outcomes for immunotherapy related to ALK-positive lung cancer.

- 1 Characterization of anti-ALK immunologic responses: Mark Awad, MD, PhD, Dana-Farber Cancer Institute.
- 2 Targeting the complement pathway in ALK positive lung cancer: Raphael Nemenoff, PhD, University of Colorado Denver
- 3 Overcoming innate immune resistance in ALK-rearranged lung cancer: Justin Gainor, MD, Massachusetts General Hospital.
- 4 In 2019, Justin Gainor received a \$100,000 award to accelerate towards a clinical trial

✓2019 GO2 Foundation for Lung Cancer = \$500,000

ALK Positive raised \$500,000 during the fall of 2019, securing a two-year research project with Dr. Christine Lovly at the Vanderbilt-Ingram Cancer Center and Dr. Trever Bivona at the UCSF Helen Diller Comprehensive Cancer Center to develop **new combination treatments involving existing ALK-targeted therapies** with the goal of extending the progression free survival of those with ALK-positive lung cancer.

✓2020 LUNGevity = \$1,000,000

By January 2020, ALK Positive has plans to seek proposals from world-leading ALK research experts to develop treatment alternatives with the likelihood of leading to significant improvement in the life expectancy and quality of life for ALK-positive lung cancer patients. This project may lead to **our first-ever clinical trial**. The ALK Positive Research Review Panel (members with research and technical expertise) and leading ALK oncologists will evaluate the proposals.

ALK POSITIVE REGISTRY DATA

Starting in 2020, ALK Positive will introduce the **world's first-ever interoperable, patient-centric cloud-based longitudinal survey specifically for ALK-positive lung cancer**. The data from hundreds of surveys completed by ALK Positive members will be made available to researchers, scientists, and pharmaceutical companies to aid in ALK-lung cancer research. Hosted by the VisionTree platform, this will deliver state-of-the-art integrated methods for **collecting and reporting patient clinical outcomes for quality research** and registry data.