What is ALK-positive lung cancer?

“ALK-positive” refers to an abnormal rearrangement of the anaplastic lymphoma kinase (ALK) gene, resulting in uncontrolled cell replication and survival, causing cancer. Researchers have discovered treatments that inhibit ALK-positive lung cancer growth – oral medications known as tyrosine kinase inhibitors (TKIs). TKIs can slow or even stop cancer progression, often with minimal adverse side effects. There is no known cure for advanced lung cancer yet; however, TKIs often increase life span by years compared to traditional lung cancer treatments. Common symptoms of lung cancer for ANY patient include a consistent cough, chest pressure, neurological symptoms, shortness of breath, wheezing, swollen lymph nodes, and/or voice changes.

Who is getting ALK-positive lung cancer?

More patients die each year of lung cancer than breast, pancreatic and colorectal cancers combined. About 4% of all lung cancers have the ALK rearrangement. This is the new face of lung cancer, only discoverable by molecular testing. Ideally this should be done at initial biopsy. There is no evidence that it is caused by environmental factors (e.g. first or second hand smoke, air pollution, radon, asbestos, chemicals) or by hereditary factors. About 50% of ALK-positive lung cancer patients are younger than age 50 when diagnosed, about 65% have never smoked and only 18% have ever smoked more than 5 cigarettes per day.

What is the ALK Positive support group?

We are a community of patients and caregivers, family, and friends affected by ALK-positive lung cancer. Our Facebook support group has 1,425+ members in over 42+ countries world-wide, and growing rapidly. We share experiences, knowledge, and emotional support to improve living with cancer, as well as extending our life expectancy. We are a patient-driven voice and advocacy group securing research and awareness for ALK-positive lung cancer.
Igniting HOPE.

ALK-positive treatment

For more advanced lung cancer, TKIs may substantially improve quality of life and life expectancy for many years. Advances in immunotherapy, chemotherapy, and radiation treatments are also helping. Traditional therapies for advanced lung cancer, such as chemotherapy and radiation alone, had less success than TKIs.

Eventually, cancer cells can change to become resistant to TKIs. When this occurs, the oncologist should consider all of these options, including combinations of these:

1. Obtain a new molecular or NGS test (from tissue or blood biopsy), to identify the most suitable treatment option;
2. Consider increasing the dose of your current TKI or switching to another TKI; and
3. Consider targeted radiation, surgery, chemotherapy, and/or immunotherapy. Clinical trials may be an option.

Patient-driven, worldwide advocacy

Encourage your ALK-positive NSCLC patients to join ALK Positive. The ALK Positive Support Group is the world’s largest ALK-positive patient community providing information, support, and empathy. We are driving research and awareness, and advocating for improved treatments.

Second Generation TKIs proven most effective

- Alectinib is the preferred first-line TKI per NCCN guidelines
- Second Gen TKIs generally are more effective than first Gen, and effective longer
- Second Gen TKIs protect the brain from cancer better than first Gen, usually with fewer side effects

Patient-driven ALK Positive Research Fund

The ALK Positive members are raising funds to advance research that may lead directly to clinical trials with the goal to further improve the quality of life and life expectancy for ALK-positive patients.

Cancer progression on TKIs

The ALK Positive Research Fund was established in 2017 in partnership with LUNGevity. We already have three $200,000 research projects underway, the results of which may ultimately benefit all lung cancer patients worldwide.

Donate at www.alkpositive.org