The new face of lung cancer.
ALK Positive Support Group gives HOPE.

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.

Who gets ALK-positive lung cancer?
Anybody with lungs can get lung cancer. About 4% of all lung cancers have the ALK rearrangement. This is the new face of lung cancer, only discoverable by molecular testing. 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 inherited traits. Among ALK Positive members, about 50% are younger than age 50 when diagnosed, about 65% never smoked and only 18% 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 1,210+ members in over 41+ countries worldwide. We share experiences, knowledge, and emotional support to improve our quality of life and extend our life expectancies. We are a patient-driven voice and advocacy group securing research and awareness for ALK-positive lung cancer.
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, your 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 with your doctor increasing the dose of your current TKI or switching to another TKI; and
3. Consider with your doctor targeted radiation, surgery, chemotherapy, and/or immunotherapy. Clinical trials may be an option.

Patient-driven, worldwide advocacy

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

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.

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.