Newly registered ALK+ International charity to fund research and advocate for rare ALK-positive cancers afflicting over 10k people each year in the UK

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- **ALK+ International launches with its mission to fund research and advocate to improve the life expectancy of ALK-positive cancer patients**
- **ALK+ International releases first patient survey at IASLC World Conference on Lung Cancer finding 91% of ALK-positive cancer patients prioritise research funding over patient support and awareness campaigns**
- **Survey finds more than two-thirds of patients would join a clinical trial even if they had treatment options available**
- **Nearly three-quarters of patients would consider local consolidated therapy without disease progression**
- **24% of ALK-positive patients wait more than one month for their biomarker test results**

LONDON, 8 August 2022 – ALK+ International today announces it has become the first charity in the UK to focus on funding research and advocating for the estimated 10,000+ people diagnosed in the UK each year with a rare cancer known as ALK (Anaplastic Lymphoma Kinase)-positive. The launch of ALK+ International coincides with a Europe-wide survey the charity released at the IASLC World Conference on Lung Cancer taking place in Vienna from 6-9 August.

ALK-positive cancer, a non-hereditary mutation-driven cancer, occurs mainly in lung cancer. Lung cancer is the third most diagnosed cancer and the biggest cause of cancer-related deaths in the UK (with around 48,500 diagnosis and more than 35,100 deaths each year). However, ALK-positive mutations are also found in other cancers such as skin melanomas and breast cancers, certain nerve, brain and bone cancers and some predominant childhood cancers like neuroblastoma and glioblastoma.

ALK-positive cancer is treated with targeted therapies – a class of drugs that precisely identify and attack certain types of cancer cells. However, ALK-positive patients will develop resistance to their medications and/or develop further mutations – rendering their treatments ineffective. There are no known causes and no cure for ALK-positive cancer once advanced.

Jamie Gibbard, Chair, ALK+ International, and an ALK-positive cancer patient, said: “I was diagnosed with stage IV ALK-positive lung cancer in 2017 at the age of 33 after experiencing a seizure. I was shocked to meet so many other young patients, including teens, all otherwise healthy, developing all forms of ALK-positive cancer and thought that something must be done. I’m thrilled to have formed ALK+ International with a group of highly motivated ALK+ patients and carers who all believe in the same mission: to increase the life expectancy of ALK-positive cancer patients.”

A survey released by ALK+ International at the IASLC World Conference on Lung Cancer 2022 finds ALK-positive cancer patients overwhelmingly prioritise research and want to be active in their care.

ALK-positive cancer patients in Europe were asked to prioritise research, patient support and public awareness in order of importance and 91% selected research as their highest priority, compared with just 2% who selected patient support and 7% awareness.

The survey also finds that ALK-positive cancer patients want to be more proactive in their treatment: 80% of respondents answered that they would be willing to try a treatment or combination of treatments even without enough evidence to prove its efficacy over standard of care. Higher still, 94% of patients surveyed want more open access to treatments based on next-generation sequencing, rather than the current systems which only allow treatments in a specific order.

Over two thirds of ALK-positive cancer patients surveyed (69.5%) would consider joining a clinical trial even if they still had treatment options available. Additionally, nearly three-quarters (72.5%), would consider local consolidative therapy proactively without disease progression, if given the option.

While mental health challenges can play a significant role in any cancer diagnosis, the data is still mixed on the offer and acceptance of services: 35% of patients were not offered mental health counselling at diagnosis. However, 40% of those offered the service elected not to use it. Twenty-two percent of patients that accepted mental health services found it useful.

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The survey also found that ALK-positive patients are experiencing a wide range of wait times for their biomarker testing. At diagnosis, 39% of respondents received their biomarker test results within two weeks, but worryingly 24% waited more than one month.

When asked where patients would like to see relevant research projects take place, 61% selected the location with the best infrastructure and 31% prefer research in their country.

Jamie adds, “It is overwhelmingly evident that ALK-positive cancer patients value research highly and want it to happen in the locations with best infrastructure and researchers. We ALK-positive patients are also in favour of clinical trials and more proactive treatments. We hope governments, pharmaceutical companies and others can use the information in this survey and patient cohorts like ours to inform their decisions.”

ALK+ International received its charity-registration in July and is launching various fundraisers and publicly advocating for research and key patient issues. ALK+ International collaborates worldwide with other cancer charities, including ALK Positive Inc, Ruth Strauss Foundation, Roy Castle Lung Cancer Foundation and others. To learn more about ALK+ International, visit *www.alkinternational.org*.

Notes to editors:

About the ALK+ International Survey of European patients

132 ALK-positive cancer patients in Europe were surveyed across 14 countries in February 2022. Over one-third of responses were from the UK; Germany and France were the second and third most represented countries.

Facts about ALK-positive lung cancer

- The ALK (anaplastic lymphoma kinase) mutation was discovered in 2007 and the first ALK targeted therapy treatment was approved in 2011.
- ALK-positive cancer occurs in 5% of all lung cancer patients (72,000 new cases and 64,000 deaths annually globally).
- Lung cancer is the leading cause of cancer death worldwide, killing more people every year than colorectal, breast and prostate cancers combined.
- Unfortunately, lung cancer is also one of the poorest funded cancers.
- ALK-positive lung cancer affects young people – about 50% of ALK-positive lung cancer patients are diagnosed before age 50, many in their 30’s.
- Most ALK-positive patients are never-smokers. There is no known cause for ALK-positive lung cancer.
- Because there are such few symptoms, about 90% of ALK-positive lung cancer patients are diagnosed at stage IV, when the cancer has spread or metastasised to other parts of the body. It is also incurable at stage IV
- ALK-positive mutations also occur in many other cancers such as large cell lymphomas, sarcomas, some breast cancers, bowel and skin melanomas, neuroblastomas, glioblastomas and more.

About ALK+ International

ALK+ International has a single mission: to increase the life expectancy of ALK+ cancer patients. We do this by fund raising for medical research, providing grants, advocating for patient interests, and collaborating with the wider medical, research, regulatory and patient groups. Learn more about us on: www.alkinternational.org. Follow us on Twitter, Instagram, Facebook and YouTube.

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