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24

ALK Positive UK
Our
Impact



ALK Positive Lung Cancer (UK) registered charity (1181171)

Support

The Support Group

We provide a private Facebook Support Group for 770 patients and their families to exchange experiences and to give and receive support.

“

This is an amazing group. It has provided a lot of help and information. All members have been supportive and welcoming and have answered many of my questions.

On average, there are **115 posts per month**, attracting **1,200 comments** and about

3,500 
reactions

During the year,

138
new members
joined the Group.



“

Definitely the best thing I ever did was join this group. Must have been near the beginning as I was diagnosed in June 2018. It has been a great help to me over the years, so many thanks.

Life Coach

We offer a Living With ALK+ Lung Cancer Coaching Service, providing 6-week online group sessions and also face-to-face coaching. Through self-management, individuals are empowered to regain control of their lives by understanding thoughts and emotions, strengthening mental resilience, identifying challenges, exploring different perspectives and setting goals.

“

You've given me a lot of helpful insight and some tools which I can use to give me a more healthy perspective on me and the situations that daily life puts me in.

10



patients attended our 6-week "Emotional Wellbeing" courses.

“

I value the support and understanding of the group. Jane has been fantastic and has helped me process my cancer diagnosis without directly discussing it. I feel in a much better head space.

8



patients/family members received 1:1 life coaching.

“

The coaching has been a true learning experience and has been so helpful in coping with my role as a cancer carer. I feel empowered and much more self-aware.

Left: Jane Woods, Life Coach



Regional Meet-ups

We arrange regional lunchtime meet-ups for patients and families. These events are important to reduce feelings of isolation and promote mental wellbeing.



Our 13 Regional Ambassadors arranged 3 subsidised lunches.



81%
of those who attended found the meetup to be valuable.

“

I just wanted to say thank you and that we really enjoyed meeting you and the group at the lunch on Saturday. It was refreshing to see people enjoying life and living with cancer.

Empowerment



We added new resources supporting the mental well being of patients and their families.



We added advice on traveling with ALK-positive LC, including an interview with a travel expert.

The Website

Our website provides a wealth of accurate and reliable information for patients, families and healthcare professionals.

Visits to our website have increased over

300% since 2020.



We developed two animated videos – the first about ALK-positive lung cancer and the second about good practice.

“

We were looking into a holiday abroad and found the website's excellent new travel advice page to be extremely helpful.

Annual Conference

Each year, we hold a weekend annual conference which is free to patients plus a companion.



International speakers from Australia and the USA were amongst the conference team leading ALK-positive lung cancer specialists.

“

It was an excellent meeting. Really impressive. Many thanks for your kind invitation to speak.
– From one of the speakers

“

I saw a patient in clinic last week and he couldn't compliment the ALK Positive conference highly enough. He was so enthusiastic about it – as was his wife. It was amazing to see and hear the passion that they both had and the positivity that they came away with. I just wanted to let you know what a fantastic job you're doing.

– From a lung cancer nurse

148

Delegates attended the 10 sessions.



Publications

We produce leaflets, guidance and reports on the diagnosis and treatment of ALK-positive lung cancer.

We produced guidance on the implications of NHS rules for continued treatment should patients have extended breaks in their treatment.

58%

of patients can expect the cancer to spread to the brain and we produced a comprehensive guide on the implications for driving licences.

“

This booklet helped me enormously in dealing with the DVLA.

Newsletter

We produce a members Newsletter 3 times a year.

“

I look forward to the Newsletters, especially reading the stories of other patients' cancer journeys.



Advocacy

Attendance at conferences

We attend regional and national conferences of healthcare professionals where we raise the profile of ALK-positive LC and campaign for best practice throughout the UK.



We attended with stands at:



British Thoracic Oncology Group

British Oncology Pharmacists Association



Cambridge Rare Cancer conference

Lung Cancer Nurses UK



Social Media

We use social media to reach both a younger audience and healthcare professionals to raise awareness of non-smoking lung cancer and ALK-positive lung cancer; and to provide information about the Charity's services.



57%
increase in Instagram followers

2.88m

views on TikTok

102%

increase in LinkedIn followers



550

Followers on Blue Sky



1,100

Followers on X

“

I love your content. Can I share this with my fellows? I'd like to use your video in my presentations.

– From an oncologist

“

I love everything about your page – it inspires and informs me every week!

Campaigning

We work with the Ruth Strauss Foundation and EGFR Positive UK on campaigns to raise awareness of lung cancer in non-smokers and the need for early diagnosis.

“

I wanted to tell you I have been admiring your amazing work during lung cancer awareness month, congratulations! The way you are bringing attention to this topic is incredible.

– From an oncologist

“

Our UK social media awards finalist “All You Need Is Lungs” campaign was aimed at the general public to raise understanding that anyone with lungs can get lung cancer. It received over 800,000 impressions across all social media platforms and these led to over 20,000 visits to website pages. Every lung cancer nurse in the UK was emailed directly.



Positive support, shared hope

I'm incredibly proud of what ALK Positive UK achieved in 2024. Our annual National Conference, attended by 148 patients and family members, continued to offer world-class expert insight, peer support, and vital networking opportunities.

We strengthened clinical guidance with real-world data surveys and broadened our best-practice materials to guide oncologists on scan frequency, MRIs and blood-clot management.

We also grew sustainably—hiring a charity manager to professionalise governance, appointing additional trustees, and maintaining our PIF-Tick accreditation for trusted health information delivery.

Our partnerships with NHS, NICE, DVLA, and other UK and European organisations

deepened—ensuring ALK-positive patient voices are heard at the highest levels.

Membership now surpasses 750 and we are firmly recognised as the UK's patient-led authority for ALK+, with a strong Net Promoter Score. In 2024, we didn't just sustain—we supported, advocated, and empowered even more patients and healthcare professionals. Here's to an even stronger 2025.

Debra

Debra Montague
Founder,
ALK Positive UK



Satisfaction

The Charity commissioned an independent survey of its members and external stakeholders.

“

ALK+UK is an absolute pleasure to work with. You always provide a great voice of the patient community and work with us as industry in a true partnership manner. – Pharma partner

Read on

to find out how our vision to Support Empower and Advocate helps us achieve these world class scores

81%

of members were very satisfied with their membership of ALK+UK.

88%

of external stakeholders were very satisfied with their dealings with ALK+UK.

Our Net Promoter Scores were world class

83%

Members

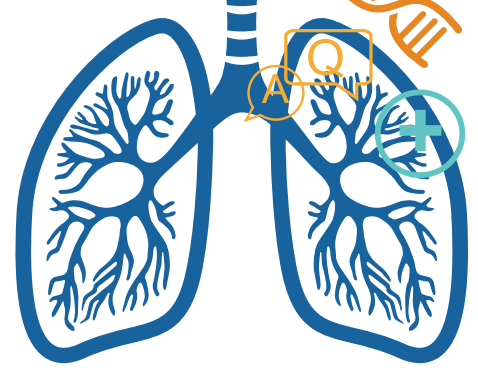
100%

Clinicians

100%

Pharma

ALK Positive UK



ALK-positive lung cancer is a relatively rare form of lung cancer caused by the abnormal rearrangement of the anaplastic lymphoma kinase gene. The vast majority of patients are non-smokers, about half are under 50 years of age when diagnosed (some are much younger), and the majority are female. Most patients are diagnosed at Stage 4.

Our Mission

ALK Positive Lung Cancer (UK) exists to:

- + **Support** the ALK-positive lung cancer patient community.
- + **Empower** people affected by ALK-positive lung cancer.
- + **Advocate** for improvements in the diagnosis, treatment and care of ALK-positive lung cancer across the UK.
- + **Represent** the voice of the ALK-positive lung cancer community.

Supports

We provide a forum where patients and their families can exchange information about their diagnosis and treatment, and where they can give and receive mutual support.

Empowers

We are a source of information for patients so that they are better informed about their condition and, as informed patients, they are empowered to ensure that their health care providers employ best practice.

Advocates

We advocate on behalf of patients to ensure that they receive a high level of care wherever they live in the UK and to promote improved patient outcomes. We campaign for early diagnosis so that more patients can be cured.

Join our growing community and help us drive ALK change



Find us at www.alkpositive.org.uk



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A registered charity in England and Wales,
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