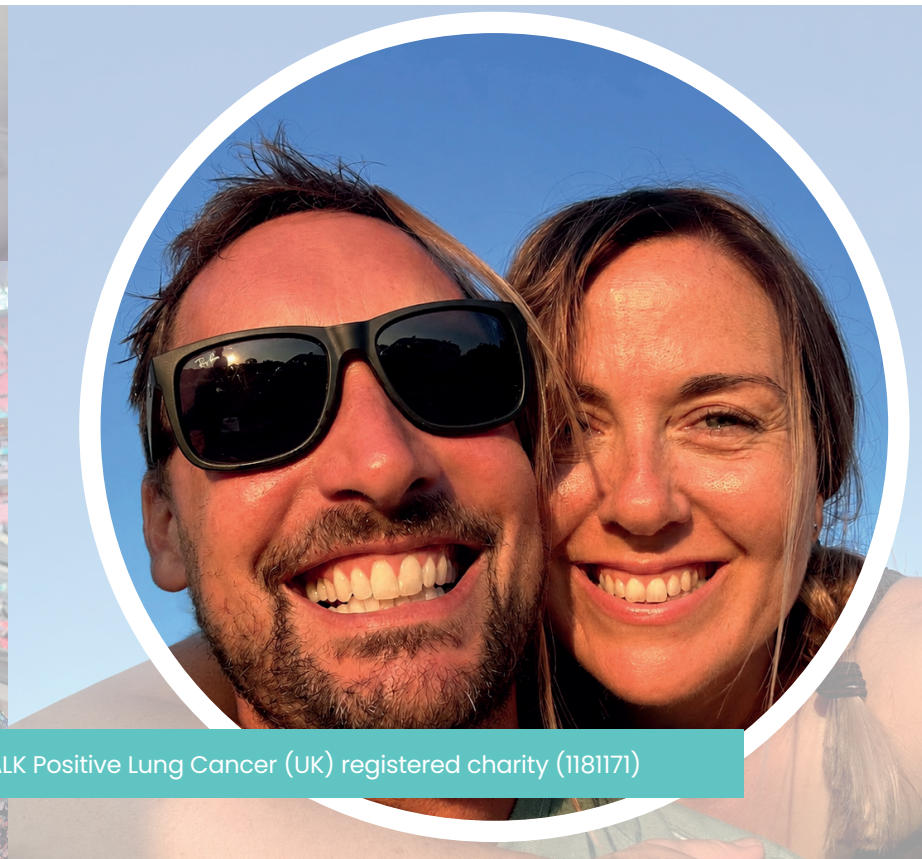




20
25

ALK Positive UK

Our
Impact



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

Growth, innovation and influence

Every year I am inspired by the resilience, generosity and determination of our members. Despite the challenges they face personally, they continue to support one another and help shape better care for everyone affected by ALK-positive lung cancer.

This year has been one of growth, innovation and influence. We have expanded the support we offer, empowered patients with trusted information and practical resources, strengthened our voice in advocating for better care, and continued to campaign for earlier diagnosis and improved outcomes. None of this would have been possible without the dedication of our volunteers, the expertise of our medical advisors, the generosity of our supporters and funders, and, above all, the willingness of our members to share their experiences so that others may benefit.

Every conference held, every local meet up organised, every survey completed and every conversation with decision-makers brings us closer to our vision of ensuring that everyone affected by ALK-positive lung cancer receives the very best care and support.

Thank you to everyone who has contributed to our journey this year. Together, we are making a real and lasting difference—and we look forward to building on these achievements in the years ahead.

Debra

Debra Montague
Founder,
ALK Positive UK



Support

The Support Group

Our private online Support Group continues to be the heart of our community. It's where members share experiences, ask questions, and offer encouragement.

A survey of group members found that 95% of respondents would recommend the group.

We also launched the ALK Positive Register so that people who choose not to join the Support Group can still engage with us.

Hardship Fund

1 in 5 members reported experiencing financial hardship as a result of their diagnosis.

In September, we launched the Brenda Cobb Hardship Fund to provide help to members in financial difficulty.

The fund is financed by Callum Cobb in memory of his mother.

2 grants awarded



“

Thank you so much. I can't tell you how much the grant means to me and my young son. – From a single mum

**117**

new members

815members
in total

On average,

350members visit
the site each day**48**new
membersjoined the
ALK Positive
registerOn average, there are 95 posts each month
attracting 1,1500 responses

“

Yesterday, I posted an introduction, and I want to thank everyone who wrote to me. I couldn't hold back my tears – I didn't expect such support! Your stories give me hope and inspire me. But now I see that together we are stronger, and thanks to your support, I have faith in tomorrow.

“

Only been a member for a few weeks and I wake up most mornings since my diagnosis on such a downer!! Until I read the posts on this group and it picks me up for the day. In my eyes you're all heroes. Thank you for that.

Regional Meet-ups

The Regional lunch groups have continued to thrive and we facilitated lunches in the Spring, Summer and Autumn. The lunches provide invaluable support, enable patients and families to meet face to face and form friendships and support networks.

The Charity believes that these social gatherings are important for the mental well-being of patients and, for this reason, the charity subsidises the cost of the lunches.

**14** lunches**3** times
a year

● In all 4 home countries

● Average of 148 members
attended each seasonal round

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.

18people attended our
6 week online group
coaching course**7**

people

received
one to one
coaching

“

I valued the connection with others and now feel less alone with this diagnosis.

Right: Jane Woods, Life Coach



“

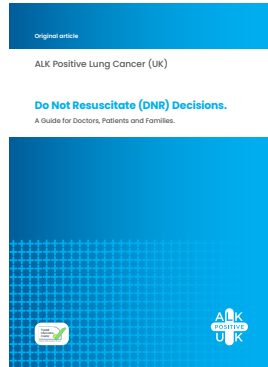
We have been meeting up for over 4 years now and are watching each other's families grow and have supported each other through our various ALK ups and downs. New faces come and we bring them into the bosom of this support system to provide empathy and comfort. It's not just a lunch – it's a lifeline. Thank you ALK Positive UK for enabling this. It's invaluable.



Empower

Publications

We added to our library of wide range of publications which give information and advice.



Do Not Resuscitate booklet, including separate information for doctors



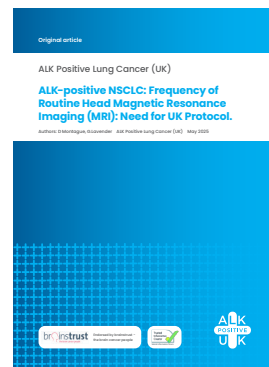
Financial Hardship Report

“

I was initially told that my health trust only does brain MRIs yearly. I pointed out the ALK Positive best practice and now will have them 6 monthly. Just keep pushing.

“

I had a brain MRI on diagnosis which was clear but my oncologist point blank refused to carry out another, saying I didn't need one unless I had symptoms. I emailed my oncologist and attached a copy of ALK+ charity's best practice guide and asked (nicely!) why he was taking this stance as it was contrary to the recommendations given by expert ALK+ oncologists. It seemed to work as a couple of weeks ago, the lung cancer nurse phoned me to say I was booked for an MRI.



Frequency of Brain MRIs

The Website

New information and resources were added to help patients and their families better understand the disease, treatment options and the services provided by the charity.

“

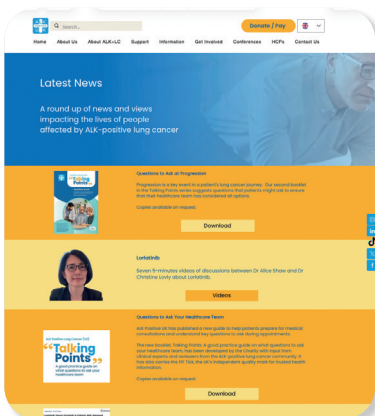
Just a quick note to say how much I love the new ALK website. It looks fabulous... easy to view and navigate too... Fab job!



1,750
visits per months

“

I already feel more positive, other websites I have seen are so dire and depressing and to read things from patients years after diagnosis is truly uplifting.



New Latest News page added



3,800
page views per month



Annual Conference

Our fourth national conference was our biggest yet and is the largest ALK positive gathering outside the USA.

10 
speakers

190
delegates

97% 
positive feedback

“

Wonderfully organised and executed with fantastic speakers and great opportunities to socialise with other ALK Positive lung cancer patients.

“

My sister and I attended the first day of the ALK conference yesterday at Heathrow, it was such a fantastic event, we met some amazing people and got to share our story and listen to other people's story's. Well done to the organisers for creating such a wonderful forum. Talking to others face to face who have gone through similar to us and our mum was really helpful and inspiring! Thank you.



Newsletter

Newsletters were sent to all members, supporters and healthcare providers in the Spring, Summer and Autumn.

3

newsletters published

“

I look forward to receiving the newsletters – they are packed with useful information.

“

Great Newsletter!



DVLA Panel

Our expert panel continued to work with the DVLA to improve driving rules for patients with brain metastases. Our guidance remains one of the most visited resources on our website.

“

Very kind but all the hard work done and led by the UK ALK team and their outstanding DVLA panel. An important document to read and digest, for UK patients, caregivers and oncologists alike.
– From Professor Sanjay Popat

“

What a great resource. It helped me get my licence back much quicker and the information about section 88 allowed me to drive whilst waiting.



Advocacy

We attended 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 worked with pharmaceutical partners to develop patient resources and sat on a wide number of expert groups and advisory panels to ensure the ALK-positive community is represented and heard.



“

I just wanted to let you know that I saw a patient in clinic last week and he couldn't compliment ALK Positive 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 their positivity. I just wanted to let you know what a fantastic job you're doing.

– From an Oncologist

We attended with stands at:



British Thoracic
Oncology Group

British Oncology
Pharmacists
Association



Cambridge
Rare Cancer
conference

Lung Cancer
Nurses UK



Campaign

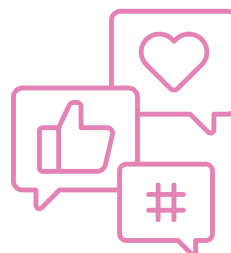
All you Need is Lungs Campaign

Our “All You Needs is Lungs” campaign with EGFR UK and the Ruth Strauss Foundation using social media was focused on the general public to raise awareness that lung cancer is not restricted to smokers. The campaign was shortlisted for a social media award.



1.6
million

social media
impressions



25k

website page views

“

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 a Lung
Cancer Nurse
Specialist

Social Media

We continue to reach clinicians, the wider public and, in particular, a younger audience with awareness – raising posts including topics such as clinical trials, our events and services.

Increased viewing on all platforms:

46%

LinkedIn

55%

Instagram

133%

TikTok

38%

BlueSky

“

Congratulations on the quality of your LinkedIn posts.
– From a clinician

“

So wonderful to have this advocacy and knowledge base supporting us after diagnosis.



Satisfaction

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

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 is a registered charity established by patients and carers. Our purposes are to:



Support

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



Empower

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



Advocate

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.



Campaign

We campaign for early diagnosis and to raise awareness of lung cancer in non smokers.



ALK Positive Lung Cancer (UK)

1 Ethley Drive
Raglan
Monmouthshire NP15 2FD
Telephone: 01600 483 004

A registered charity in England and Wales, registration number 1181171.

A registered charity in Scotland, registration number SC053692.



For further information
visit our website:
www.alkpositive.org.uk

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