



ALK Positive UK

Extract-Trustees' Annual Report 2025

Key Achievements

- ✓ 190 members and their families attend the annual weekend conference
- ✓ 117 new members joined the Support Group
- ✓ 14 regional lunches held three times
- ✓ 3 new publications issued
- ✓ Hardship Fund established
- ✓ CEO appointed
- ✓ Fundraising and donations reached a new peak



Conference

We held our fourth national conference for people living with ALK-positive lung cancer and their families, welcoming 190 delegates to London. The event brought together some of the UK's leading experts in ALK-positive lung cancer, providing delegates with the opportunity to hear the latest developments in treatment and care, ask questions, and share experiences with others facing similar challenges.

The conference was the largest gathering of ALK-positive patients and their families in the world outside the USA. It was funded in part through educational grants from pharmaceutical companies. Feedback from delegates was overwhelmingly positive, with particular praise for the quality of the speakers, the organisation of the event and the venue. Videos of all presentations, together with a vox pop capturing delegates' experiences, are available on our website.

Living with ALK+ Coaching Service

We continued to offer our *Living with ALK+ Lung Cancer Coaching Service*, providing members with six-week online group coaching programmes and one-to-one sessions. A diagnosis of cancer can have a profound impact on confidence, identity and emotional wellbeing. Through guided self-management, participants develop practical strategies to understand their thoughts and emotions, build resilience, overcome challenges, explore new perspectives and set realistic goals.

The programme has received consistently positive feedback and continues to play an important role in helping members regain confidence and take greater control of their lives.

Regional Ambassadors

Our network of fourteen volunteer Regional Ambassadors continued to strengthen local support across the UK by organising regular lunches for members. These meet-ups provide valuable opportunities for people to connect with others who understand the unique challenges of living with ALK-positive lung cancer, helping to reduce isolation and improve mental wellbeing.

Recognising the importance of these events, the charity subsidises the cost of meals to encourage participation. We have also developed guidance and resources to equip our Ambassadors to deliver this increasingly important aspect of our support programme.

Website

During the year we completed a major upgrade of our website, placing greater emphasis on the support available to people who have recently been diagnosed with ALK-positive lung cancer.

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. A key objective is to empower patients with reliable, accessible information so they can play an active role in decisions about their care and secure the best possible outcomes.

We also introduced a *Latest News* section to keep members informed about developments in ALK-positive lung cancer, treatment advances and the activities of the charity. Recognising the importance of emotional wellbeing, we continued to expand the range of wellbeing resources available on the website.

Website usage has continued to grow significantly, increasing from around 500 visits per month in 2020 to approximately 2,000 visits per month in 2025, demonstrating the increasing value of the website as a trusted source of information and support.

Facebook Community

Our Facebook community continued to flourish during the year, with membership increasing by 119 people.

The group provides a welcoming and supportive environment where members can share experiences, ask questions and offer encouragement to one another. It is particularly encouraging that new members consistently receive a warm welcome from the community. A survey of group members found that 95% of respondents would recommend the group to other people living with ALK-positive lung cancer.

To ensure that people who prefer not to use Facebook can still stay connected with the charity, we also introduced the ALK Positive Register.

Newsletters

We published Spring, Summer and Autumn newsletters, keeping members informed about advances in the treatment of ALK-positive lung cancer, developments within the charity and opportunities to become involved in our activities.

Brenda Cobb Hardship Fund

During the year we established the Brenda Cobb Hardship Fund, generously funded by Callum Cobb in memory of his mother.

The Fund provides financial assistance to members experiencing hardship as a direct consequence of their diagnosis. Two grants were awarded during the year, providing practical support to members when they needed it most.

DVLA Panel

Our three-member DVLA Panel continued to engage with the Driver and Vehicle Licensing Agency to seek changes to rules affecting people with brain tumours, which we believe can be disproportionately restrictive for some of our members.

The Panel also provides individual advice and guidance to members navigating these complex regulations. Our guidance on driving regulations for people with brain tumours continues to be one of the most widely used resources on our website.

Publications

Providing accurate, practical information remains central to our mission of empowering patients.

During the year we published a revised *Do Not Resuscitate* booklet for patients and their families, together with a companion leaflet for healthcare professionals.

We also published our *Financial Hardship Report*, based on data gathered from members participating in a Europe-wide survey. The findings showed that one in five respondents experienced significant financial hardship as a direct result of their diagnosis.

Our report on the *Frequency of Brain MRIs* used real-world patient data to demonstrate that many members were not receiving scans in line with recognised best practice. We have received encouraging feedback from members whose clinicians have increased the frequency of their MRI scans following publication of the report—a powerful example of patient empowerment leading to improvements in care.

In addition, we produced a new four-page leaflet highlighting the range of support and services available through the charity.

Online Coffee Mornings

Our monthly online coffee mornings continued to provide a friendly, informal opportunity for members to meet, share experiences and support one another. These sessions remain an important part of our commitment to reducing isolation and fostering a strong, connected ALK Positive UK community.

Advocacy

Advocacy remains at the heart of ALK Positive UK's work. By gathering real-world evidence, working alongside healthcare professionals and decision-makers, and representing the experiences of people living with ALK-positive lung cancer, we continue to influence improvements in diagnosis, treatment and care.

Representation

We continued to ensure that the voices of people living with ALK-positive lung cancer were heard by organisations responsible for shaping policy and access to treatment.

During the year, we responded to consultations from the National Institute for Health and Care Excellence (NICE) and its Scottish equivalent on new treatments for ALK-positive lung cancer. We also participated in meetings to provide the patient perspective, helping decision-makers understand the real-world impact of their recommendations.

We worked with a wide range of organisations to:

- raise awareness of ALK Positive UK and the needs of our community
- promote best practice in diagnosis, treatment and care
- contribute the patient perspective to publications and projects
- increase awareness of lung cancer in never-smokers and light smokers
- campaign for early diagnosis.

UK Collaboration

We strengthened our relationships with organisations in Scotland, Wales and Northern Ireland and were supported by three volunteer patient representatives who help raise awareness of the charity and advocate for patients within their regions.

International Collaboration

Our influence extends beyond the UK through strong partnerships with organisations across Europe. These collaborations enable us to share knowledge, learn from best practice and ensure that the experiences of UK patients contribute to wider discussions on improving outcomes for people living with ALK-positive lung cancer.

Our Chair continues to play a leading role internationally as President of Lung Cancer Europe, a Board member of ALK Positive Europe and a member of the European Lung Cancer Foundation Patient Advisory Committee.

Conferences and Professional Engagement

Sharing knowledge and learning from others are essential to improving patient care. During the year we presented abstracts at key stakeholder conferences and attended a wide range of professional meetings, including:

- British Thoracic Oncology Group (BTOG) Conferences
- UK Lung Cancer Nurse Conference

- British Oncology Pharmacy Association (BOPA) Conference
- UK Lung Cancer Coalition (UKLCC) Conference
- Lung Cancer Europe
- Wales Cancer Alliance Conference
- Northern Ireland Cancer Charities Conference

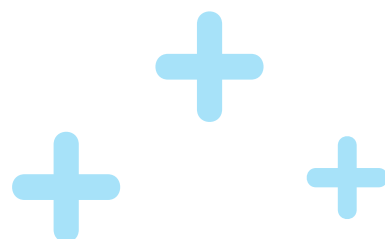
Participation in these events enables us to build relationships with clinicians, researchers, policymakers and other charities while ensuring that the experiences of people living with ALK-positive lung cancer are represented at every opportunity.

Campaigning

We remained committed to raising awareness of lung cancer and improving early diagnosis.

During the year, we launched the fourth phase of the **All You Need Is Lungs** campaign in partnership with EGFR Positive UK and the Ruth Strauss Foundation. The purpose of the campaign was to raise awareness that lung cancer can affect people regardless of their age and smoking history and reinforcing the importance of early investigation of persistent symptoms.

The campaign was shortlisted for a national Social Media award.



Social Media

Our social media channels continued to expand their reach, enabling us to inform, educate and support a growing audience.

Follower numbers increased by 46% on LinkedIn, 55% on Instagram, 133% on TikTok and 38% on BlueSky. We also maintained an active presence on X (formerly Twitter), using our platforms to share trusted information, promote our campaigns and celebrate the achievements of our community.

As our digital reach continues to grow, social media remains an increasingly important tool for connecting with patients, supporting healthcare professionals and raising awareness of ALK-positive lung cancer.

Governance

During the year, the trustees had two face-to-face meetings, an AGM at the start of the year and a half-year review, and eighteen meetings were held electronically, by email or online. The Trustees have had regard to the guidance issued by the Charity Commission on public benefit.

In September, we appointed Lynsey Conway as a part-time CEO. Lynsey has over 35 years' experience working as a healthcare communicator, 20 of them with the Lung Cancer Coalition (UKLCC). Lynsey's appointment was an important step in strengthening the charity's long term sustainability and in supporting effective succession planning.

We appointed trustees to be Link Trustees to provide a link between the Board and the Executive and to act as sounding boards for the CEO.

We used Artificial Intelligence for administrative purposes, to summarise reports, including clinical trials, and to analyse data. We have three AI-generated podcasts on the website.

Financial Review

The Charity had a balance of £234,526 at the end of the year, an increase of £58K. The principal reasons for the surplus were increased fundraising and donations, including In Memorial. There were some large individual donations.

We are very grateful to all those who have donated or fundraised, including those who make regular monthly donations.

However, we cannot rely on this high level of fundraising, donations and grants continuing and, with increased staffing costs and the growth of our annual conference, it is expected that we will draw on balances for the next few years.

The Charity is risk averse and we ensure that we have sufficient funds in hand before committing ourselves to expenditure.

We are registered with the Fundraising Regulator and this requires us to comply with their fundraising standards.

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.



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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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