

ALK POSITIVE LUNG CANCER (UK)

Charity No. 1181171

TRUSTEES' ANNUAL REPORT

1 January 2024 to 31 December 2024

The Charity was established in December 2018 and this is the Trustees' sixth Annual Report.

ALK-Positive lung cancer is a relatively rare form of lung cancer caused by a genetic malfunction and comprises about 3% of all lung cancers. Patients are, on average, much younger than most other lung cancer patients and are usually never-smokers.

1. Objectives and Activities

The objectives of the Charity are to relieve sickness and to preserve and protect good health of UK anaplastic lymphoma kinase (ALK) positive lung cancer patients by: -

- a. providing an information resource, in particular access to information about latest developments and clinical trials.
- b. Identifying and locating UK ALK-positive patients and offering support and guidance on the location of UK ALK specialists and services.
- c. Liaising with and influencing decision makers, e.g., NICE, NHS, DVLA;
- d. Raising awareness of ALK-positive lung cancer, particularly amongst the medical profession to promote the best treatment for patients.
- e. Liaising with relevant organisations, in particular EGFR Positive UK, Ruth Strauss Foundation and the pharmaceutical industry.
- f. Raising funds for the above purposes.

2. Our Vision

We want everyone in the UK who is diagnosed with ALK-positive lung cancer to thrive and live a long and fulfilling life unhindered by their disease.

3. Our Mission

Alk Positive Lung Cancer (UK) exists to

- **Support** the ALK+ 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

4. Our Values

- We are welcoming in our approach and put the needs and interests of patients with ALK-positive lung cancer and their families first, treating them with the respect and empathy that they deserve.
- We are passionate about our work – our passion is driven by a deep personal connection to ALK-positive lung cancer which means we are highly committed and determined.
- We always act with professionalism and integrity and our activities are based on the best available evidence.

4. Achievements and Performance

A group of 18 patients and supporters came together in July 2018 with the aim of establishing a UK group of ALK-positive patients who could exchange experiences and give and receive mutual support. At our second meeting in October 2018, it was decided to form a registered charity and the Charity was registered by the Charity Commission on 14 December 2018. We started with a £1,000 loan from the Treasurer.

Our achievements and performance in our six years have greatly exceeded our expectations. The main activities undertaken in 2024 to further our objectives are set out below. In this report, “members” refers to members of the charity’s private Facebook Support Group.

4.1 Support and Empowerment

Conference

We held our third national conference for ALK-positive patients and their families. 148 delegates attended the conference which was held in London and they heard from and questioned some of the UK’s leading ALK-positive experts. The conference was the largest gathering of ALK-positive patients and their families in the world, outside the USA. It was funded, in part, by grants from pharmaceutical companies. The conference was a huge success and videos of all sessions are on our website along with a vox pop of what the delegates thought. We received very positive feedback about the venue, organisation and quality of the speakers.

Life Coach

We offered a Living With ALK+ Lung Cancer Coaching Service, providing 6-week online group sessions. A cancer diagnosis can cause loss of identity and self. 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. We have had very positive feedback from participants.

Regional Ambassadors

Twelve of our members from many parts of the country have volunteered to be Regional Ambassadors to arrange local meet-ups for members. 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 meals.

We produced guidelines for the Ambassadors to equip them in delivering what has become a key component of our service to members.

Website

Additional information was added to the website which provides information about the Charity and is a source of information for members to be better informed about ALK-positive lung cancer. One of our principal aims is to empower patients to enable them to ensure that they get the best possible care.

We developed two animated videos – the first explaining what ALK-positive lung cancer is and the second is about good practice. Both animations have been used in our social media output and are available on the website.

We place considerable importance on the mental wellbeing on patients and we provide several resources on the website.

Visits to the website have increased from about 500 per month in 2020 to 2000 per month in 2024.

A working party of members was established to review the website and prepare a brief for its redesign to focus on newly diagnosed patients. We asked newly diagnosed patients how we could make the website easier for them to find the information that they were looking for.

Facebook Page

The Facebook page is a great success and the number of members increased from 638 to 748 during the year. Each day, there are postings by patients sharing experiences and giving and receiving emotional support. It is particularly pleasing that new members receive a very warm welcome from existing members. A survey of followers showed that 95% of respondents would recommend the group to other ALK-positive patients.

Newsletters

We produced newsletters in Spring, Summer and Autumn which inform members of developments in the treatment of ALK-positive lung cancer and the activities of the charity.

Medical & Scientific Advisory Panel

We had a Medical & Scientific Advisory Panel comprising two retired GPs and a Professor Emeritus of Molecular Oncology, all ALK-positive patients. The Panel produced guidance on the NHS rules concerning extended breaks of treatment.

During the year, the Panel was reconstituted and now comprises working lung cancer oncologists and members of relevant allied professions.

DVLA Panel

The Panel of three members continued to interact with the DVLA with the objective of amending their rules which we consider to be unreasonably harsh for our members. The Panel is able to give advice to members on the application of these rules.

During the year, the Panel produced an authoritative guidance for members on the DVLA rules on driving and brain tumours.

4.2 Advocacy

Surveys

For six years, we have conducted surveys of our members to ascertain real-world data on all aspects of their diagnosis, treatment and care. The data produced enables us to identify deficiencies and variations in the level of services our members receive, including regional variations. We use this information at meetings with oncologists and nurses and at conferences to advocate for best practice. During the year, we conducted a survey of patients' experiences of their treatment for blood clots.

We attended the national conferences of

- British Thoracic Oncology Group
- All Ireland Lung Cancer Coalition
- Lung Cancer Nurses UK
- Cambridge Rare Diseases Conference

We also attended other meetings with healthcare professionals where we raised awareness of the Charity and of ALK-positive lung cancer and advocated on behalf of patients. It is important that healthcare professionals are aware of the Charity and the support that we provide so that they direct their patients to us. The growth in members indicates that we are having some success in raising this awareness.

We had abstracts published at key stakeholder conferences –

- British Thoracic Oncology Group
- British Oncology Pharmacists Association
- Lung Cancer Nurses UK
- European Lung Cancer Conference

We continued to work with the Christie Hospital on the development of an Educational Portal for oncologists, their teams and patients and we are supporting the development of the patient Resources section.

We continued to campaign for early diagnosis of lung cancer and a fourth phase of our “See Through the Symptoms Campaign with EGFR Positive UK and the Ruth Strauss Foundation was launched. This campaign is targeted at primary care.

We were members of

- UK Lung Cancer Coalition
- Lung Cancer Europe
- Cancer52
- European Lung Foundation
- Genetic Alliance

To coincide with Lung Cancer Awareness Month in November and again in collaboration the EGFR UK and Ruth Strauss Foundation, we launched “All You Need is Lungs” campaign aimed at the general public and social media users.

We have continued to grow our use of social media and are active on Twitter, LinkedIn and Instagram, TikTok and BlueSky

4.3 Representation

We were consulted by the National Institute for Health and Care (NICE) on applications by pharmaceutical companies for approval of their products relevant to ALK-positive lung cancer and we attended online meetings with NICE (and its Scottish equivalent) where we have given the patients’ perspective.

We continued to collaborate with several pharmaceutical companies on the development of resources for patients and participated in other working groups and advisory boards.

Working with these organisations and groups gives us access to information about latest developments and raises the Charity’s profile with key clinicians.

We developed links with organisations in the Scottish, Welsh and Northern Ireland regions. We registered with the Scottish Charity Regulator and joined the Scottish Cancer Coalition. We have appointed one of our Trustees who lives in Scotland our representative. We have become members of the Wales Cancer Coalition and the Northern Ireland Cancer Charities Coalition. We joined with other organisations in lobbying the NI Health Executive about the lack of resources in NI for diagnosing and treating lung cancer.

We have developed links with relevant organisations throughout Europe. Our Chair is Vice-president of Lung Cancer Europe, a Board member of ALK Positive Europe and a member of the European Lung Cancer Foundation Patient Advisory Committee.

5. Financial Review

Our members undertook a wide range of activities which, together with those activities organised by the charity, raised over £70,000. We are very grateful to these members.

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

We are also very grateful to all those members who are now making regular monthly donations.

The Charity had £ 177,023 in its bank account at the end of the year, a year-on-year increase of £68K. The principal reasons for the surplus were increased fundraising and donations. With uncertainty about funding of future conferences and the need to employ a part-time CEO, it is expected that we will draw on balances in future years.

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

6. Structure, Governance and Management

The Charity is a Charitable Incorporated Organisation and the governing document is its Constitution which provides that there shall be between three and eight Trustees.

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 held electronically, by email or Zoom. The Trustees have had regard to the guidance issued by the Charity Commission on public benefit.

Three new trustees were appointed and one left at the end of the year – details at paragraph 8.

Day-to-day management is delegated to the Senior Leadership Team comprising the Chair, Treasurer, Secretary and Chief Officer.

Following a review of administration, we appointed a part-time Manager who is tasked with reviewing our administrative arrangements, implementing our PIF Tick obligations and putting the charity on a sustainable basis.

We started to use Monday.com as a project management tool and we are making greater use of Google Share to store and share documents.

Following our successful Strategic Planning meeting towards the end of 2023, we adopted a 10-point Action Plan for 2024.

Our first official complaint was received at the end of 2023 and resulted in a review of attendance by bereaved relatives at regional lunches.

The Charity has policies in place concerning –

- Code of Conduct
- Equality and Diversity
- Privacy
- Use of Images & Quotes
- Complaints Procedure
- Financial Control
- Trustee Expenses
- Conflicts of Interest
- Fundraising
- Whistle-blowing

7. Reference and Administrative Details

Charity Name	ALK Positive Lung Cancer (UK)
Other names the charity uses	ALK Positive UK and ALK+UK
Registered charity number	1181171
Charity's principal address	1 Ethley Drive Raglan Monmouthshire NP15 2FD

8. Names of the Charity Trustees who Managed the Charity in 2024

Trustee Name	Office (if any)	Dates Acted if not for whole Year
Debra Montague	Chair	
Graham Lavender	Secretary	
Rebecca Stebbings		To 29/12/24
Angela Field		
Andy McKay	Treasurer	
Kathy Redmond		From 15/2/24
Geoff Otterman		From 11/10/24
Callum Cobb		From 4/12/24

Corporate Trustees – n/a

Names of Trustees holding title to property belonging to the Charity – n/a

Funds held as custodian trustees on behalf of others – nil.

9. Declarations

The Trustees declare that they have approved the Trustees' Report as above.

Signed on behalf of the Charity's Trustees

Signatures	G H Lavender	D L Montague
Full Names	Graham Herbert Lavender	Debra Louise Montague
Positions	Secretary	Chair
Date	1 September 2025	1 September 2025