

ALK POSITIVE LUNG CANCER (UK)

Charity No. 1181171

TRUSTEES' ANNUAL REPORT

1 January 2023 to 31 December 2023

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

ALK-Positive lung cancer is a relatively rare form of lung cancer caused by a genetic malfunction and comprises less than 4% 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 five years have greatly exceeded our expectations. The main activities undertaken in 2023 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 second national conference for ALK-positive patients and their families. 140 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 a huge success and videos of all sessions are on our website along with a vox pop of some of the delegates. 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.

.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.

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.

Facebook Page

The Facebook page is a great success and the number of members increased from 543 to 638 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.

Medical & Scientific Panel

We have a Medical & Scientific Advisory Panel comprising two retired GPs and a Professor emeritus of Molecular Oncology, all ALK-positive patients. The panel provide advice to the Trustees and ensure that all our publications reach a high standard.

We became aware that, inappropriately in our opinion, some members had Do Not Resuscitate orders placed on their records. The Panel produced a guidance booklet to help inform doctors, patients and families, to facilitate discussions between them and to guide the doctor's decision about whether to sign a DNR order for a patient with ALK-positive LC.

We published a booklet on how to complain to the NHS.

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 unreasonable harsh for our members. The Panel is able to give advice to members of the application of these rules.

4.2 Advocacy

Surveys

For five 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 enable 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 gathered data on

- Mental Health
- Side Effects
- Membership Details

We attended the national conferences of

- British Thoracic Oncology Group
- Lung Cancer Nurses UK
- Wales Cancer Alliance
- Patient Centricity & Engagement Conference
- International Patient Advocacy Symposium (funded)
- International Brain Tumour Association (funded)

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

We worked 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 third phase of our “See Through the Symptoms Campaign with EGFR Positive UK and the Ruth Strauss Foundation was launched and received the annual Lung Cancer Europe’s (LuCE) award for raising awareness. This campaign is targeted at primary care.

Our Chair was appointed to the board of LuCE.

We were members of

- UK Lung Cancer Coalition
- International Association for the Study of Lung Cancer
- Cancer52
- European Lung Foundation
- Genetic Alliance
- Lung Cancer Europe

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 continued to seek opportunities to garner support for the production of guidelines for the management of ALK-positive lung cancer and we are using data from our members’ surveys to provide the evidence for guidelines.

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

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 and we attended online meetings with NICE (and its Scottish equivalent) where we have given the patients’ perspective.

We collaborated with several pharmaceutical companies on the development of resources for patients, including Roche (mental health), Pfizer (three podcasts), Takeda (expert patient) and Makara Health (partnership working).

We participated in Working Groups/Advisory Boards of

- Manchester Gnostic Delivery Group
- European Lung Foundation
- Focus Group for Biomarker Testing
- Jansen Patient Advisory Board
- Takeda Patient Advisory Board
- Ruth Strauss Foundation Grants Panel
- From Testing to Targeted Treatment
- Macmillan Gnostic Group
- SE London Early Diagnosis Group
- Novartis Patient Advisory Board
- Clinical Expert Group for LC
- Screening of LC in Europe Project

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

5. Financial Review

Our members undertook a wide range of activities which, together with those activities organised by the charity, raised £56,000. 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 £109,593 in its bank account at the end of the year, including £9,631 of restricted funds. This was a year-on-year decrease of £14,051. The principal increases in expenditure arose from annual conference, social media, staffing and PIF Tick accreditation

We introduced the Xero accountancy package at the start of the year and engaged a Finance Assistance to manage this. The Charity is risk averse. 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.

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 Chief Executive Officer, our first paid appointment. The CEO was tasked with reviewing our administrative arrangements, implementing our PIF Tick obligations and putting the charity on a sustainable basis.

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

We held a two-day strategic planning event attended by trustees, Regional Ambassadors and members of our two panels. By the end of the event, we had drafted new

- Vision Statement
- Values Statement
- Mission Statement
- Strategic Objectives

We decided to seek the PIF Tick award which shows that an organisation's health information has been through a professional and robust production process. The application process was extremely time consuming and made us think in detail of the processes that we need. We were delighted to receive the award in September and we are the only lung cancer charity in the UK to have the award. All new publications and reviews of existing publications will be subject to the processes we now have in place.

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	Old Carw Farmhouse Carrow Hill St Brides Netherwent Caldicot Monmouthshire NP16 3AU

8. Names of the Charity Trustees who Managed the Charity in 2023

Trustee Name	Office (if any)	Dates Acted if not for whole Year	Name of person or body entitled to appoint trustee (if any)
Debra Montague	Chair		
Graham Lavender	Secretary		
Rebecca Stebbings			
Angela Field			
Lynne Murtha			
Shaun Hill	Treasurer	6 Jan – 31 Dec	
Duncan Edmonstone		10 March – 31 August	
Andy McKay		27 Nov – 31 Dec	

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	31 July 2024	31 July 2024