

Financial Review

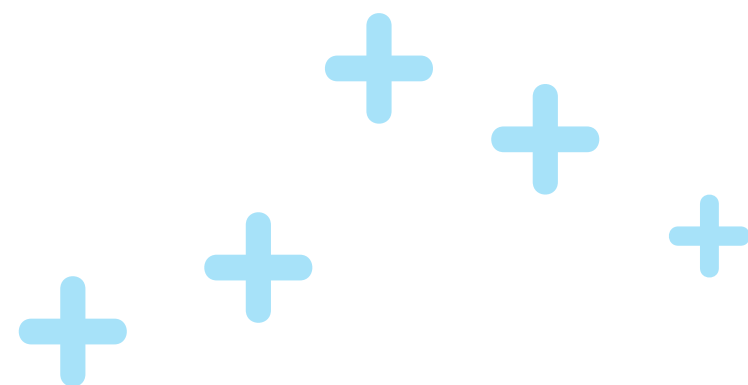
Our members undertook a wide range of activities which, together with activities organised by the charity, raised over £70,000. We are very grateful to these members.

We are 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 £176,978 in its bank account at the end of the year, a year-on-year increase of £67,278. The principal reasons for the surplus were increased fundraising and donations.

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



ALK Positive Lung Cancer (UK)
1 Ethley Drive, Raglan,
Monmouthshire, NP15 2FD

A registered charity in England and Wales,
registration number 1181171

ALK Positive UK

Extract – Trustees' Annual Report 2024

Key Achievements

- ✓ Weekend conference for 148 patients and their close families
- ✓ Establishment of 12 Regional Ambassadors
- ✓ PIF Tick accreditation
- ✓ Expansion of social media output
- ✓ Early Diagnosis campaign targeted at primary care professionals
- ✓ Public campaign aimed at raising awareness of non-smoking lung cancer
- ✓ Strategic Review carried out

Support and Empowerment

Conference

We held our second 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 a huge success and videos of all sessions are on our website along with a vox pop of what the delegates thought. 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.

Website

Additional content was added to the website which provides information about the charity and is a source of information for members so that they are 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.

Regional Ambassadors

Thirteen of our members representing most 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.

Life Coach

We offered a Living With ALK+ Lung Cancer Coaching Service, providing 6-week online group sessions and also one-to-one 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.

Advocacy

Facebook Page

The Facebook page is a great success and there were 138 new members during the year, bringing the total to 748. 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 and Scientific Panel

The panel was reconstituted during the year and now comprises working healthcare professionals including thoracic oncologists, an anaesthesia and pain consultant, a clinical senior lecturer in Psychosocial Oncology, a senior oncology pharmacist and an intensive care doctor.

DVLA Panel

The panel of three patient 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.

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

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.

Representation

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

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. This campaign has been shortlisted for a national award.

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

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 as 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.

