

ALK Positive UK

Extract – Trustees' Annual Report 2023

Key Achievements

- ✓ Weekend conference for 140 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. 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.

Advocacy

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 and 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.

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
- Patient Centricity & Engagement Conference
- Lung Cancer Nurses UK
- International Patient Advocacy Symposium (funded)
- Wales Cancer Alliance
- 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
- British Oncology Pharmacists Association
- Lung Cancer Nurses UK
- 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.

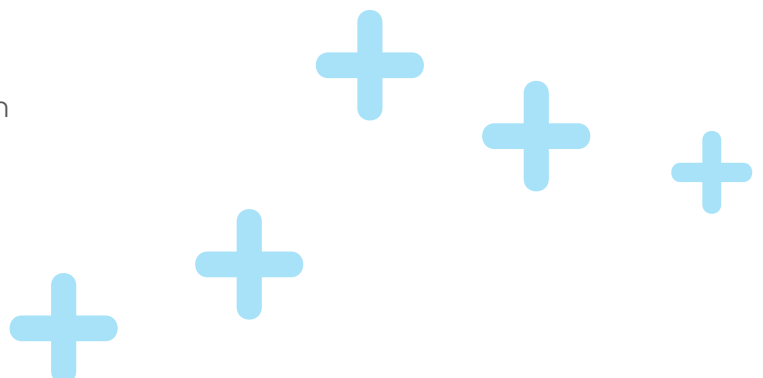
We were members of:

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



Representation

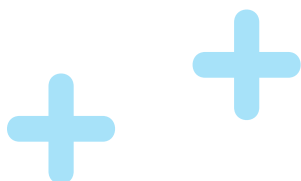
We were consulted by the National Institute for Health and Care (NICE) on applications by pharmaceutical companies for approval of their products and we attended online meetings with NICE (and its Scottish equivalent) where we have given the patients' perspective.

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 Genomic Delivery Group
- From Testing to Targeted Treatment
- European Lung Foundation
- Macmillan Genomic Group
- Focus Group for Biomarker Testing
- SE London Early Diagnosis Group
- Jansen Patient Advisory Board
- Novartis Patient Advisory Board
- Takeda Patient Advisory Board
- Clinical Expert Group for LC
- Ruth Strauss Foundation Grants Panel
- 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.



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.

ALK Positive Lung Cancer (UK)

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A registered charity in England and Wales,
registration number 1181171