

ALK POSITIVE LUNG CANCER (UK)

Charity No. 1181171

TRUSTEES' ANNUAL REPORT

1 January 2022 to 31 December 2022

The Charity was established in December 2018 and this is the Trustees' fourth 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 Roy Castle Lung Cancer 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 receive the best care possible
- to live their best lives possible
- to live for as long as possible

To achieve this, we

- **Support** patients by providing a secure platform where they can give and receive mutual support and exchange experiences about their treatment
- **Empower** patients by providing information that enables them to demand a high level of care
- **Advocate** on behalf of patients to ensure that they receive the best care wherever they live in the UK

3. 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 first four years have greatly exceeded our expectations. The main activities undertaken in 2022 to further our objectives were –

3.1 Support and Empowerment

Conference

We held our first national conference for ALK-positive patients and their families. 110 delegates attended the conference which was held in Birmingham 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 by grants from pharmaceutical companies.

Life Coach

We launch 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

Towards the end of the year, twelve of our members from many parts of the country 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.

Other social events have included a speedboat down the Thames and a Thames-side walk.

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 users increased from 450 to 543 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 established a Medical & Scientific Advisory Panel comprising two retired GPs and a Professor emeritus of Molecular Oncology, all ALK-positive patients. The panel will provide advice to the Trustees and ensure that all our publications reach a high standard. Medical advice will not be provided to members.

Surveys

We carry out 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

- Brain Metastases
- Alectinib
- Side effects
- Membership details
- Brigatinib
- Fatigue
- Lorlatinib
- Demand for social gatherings

Online Activities

We hold weekly exercise sessions which are recorded and placed on the website and monthly coffee mornings.

3.2 Advocacy

We attended the national conferences of

- British Thoracic Oncology Group
- Lung Cancer Nurses UK
- Cancer Research UK

The LCNUK was their first face-to-face conference since the pandemic. Over 300 lung cancer nurses from throughout the UK attended and we spent a very busy two days talking to them.

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
- World Conference on Lung Cancer
- International Association for the Study of Lung Cancer

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 worked with several pharmaceutical companies on the development of resources for patients.

We worked with other organisations to raise awareness of rare lung cancers and were members of

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

We published several resources –

- Mental health poster
- Biomarker testing
- Molecular Mechanisms and Treatment Strategies.
- Need for National Guidelines (published in medical press)
- Importance of Oncogene-Driven LC support Groups
- Charity Brochure

Our DVLA panel was active in lobbying the DVLA to amend their rules about driving with brain metastases.

We have opened up channels of communications with LC oncologists and nurse specialists in all hospitals throughout the UK so that we can tell them about the support that the charity can offer to their patients.

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

Our “See Through the Symptoms” early diagnosis campaign, developed with EGFR Positive UK and the Ruth Strauss Foundation, was taken up by Gateway C, the leading GP education provider, and they now provide an online never-smoker lung cancer course as part of their curriculum.

We led on the development of the Oncogene-Driven Lung Cancer Patient Alliance, which leading ALK experts are supporting. This will be the platform where we engage with policy makers to ensure that never-smoking lung cancer is included in all lung cancer strategies. Professor Alastair Greystoke agreed to be the honorary Clinical Lead. We commissioned an animated video on the role of support groups and the benefits they offer patients.

3.3 Fundraising

We hit the ground running at the beginning of the year with the Sapphire Ball. 115 people had an amazing night and an incredible total of over £15,000 was raised for the charity.

Our members undertook a wide range of activities which, together with those activities organised by the charity, raised £55,000. We are very grateful to these members whose activities included

- Zip Wire in North Wales
- Rollerblading
- Marathons
- Charity Gig
- Walking
- Sky Dive
- Sale of cakes
- Abseil
- Half Marathons
- 60s/70s evening
- Race night
- Mountain climbing
- Playing bridge
- Cycling

We launched a “Many More” Standing Order campaign. We chose this name as we want patients to

- Enjoy many more birthdays
- Take many more holidays
- Go on many more walks
- Make many more memories
- Do the things that they like many more times

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

4. Financial Review

The Charity had £128,120 in its bank account at the end of the year, including £4,477 of restricted funds. This was a year-on-year increase of £16,029 due to the high level of fundraising. In October, the Trustees held a strategic planning meeting to determine actions to ensure that the charity has a sustainable base and to develop it to “the next level”.

We do not occupy premises and we do not currently employ staff, although we commission services. We have a very low level of fixed costs, e.g., website maintenance, subscriptions to other organisations, insurance, and our end of year balances are largely available to promote the Charity’s objectives.

5. Structure, Governance and Management

The Charity is a Charitable Incorporated Organisation and the governing document is its Constitution.

The Constitution provides that there shall be between three and eight Trustees.

The Trustees have had regard to the guidance issued by the Charity Commission on public benefit.

We have policies in place concerning –

Code of Conduct
Complaints Procedure
Conflicts of Interest
Equality and Diversity
Financial Control
Fundraising
Privacy
Trustee Expenses

We sought advice on the General Data Protection Regulations to ensure that we are compliant.

We were delighted that Jackie Fenemore, a leading lung cancer nurse specialist, agreed to join our panel of Honorary Clinical Advisors

6. 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

7. Names of the Charity Trustees who Managed the Charity in 2022

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 & Treasurer		
Rebecca Stebbings			
Susan Eastwood		Until 31/07/2022	
Angela Field			

Tessa Rust		Until 20/02/2022	
Lynne Murtha			
Paula Tully		From 20/02/2022	

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.

8. 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	16 September 2023	16 September 2023