

ALK POSITIVE LUNG CANCER (UK)

Charity No. 1181171

**TRUSTEES' ANNUAL REPORT**

**1 January 2021 to 31 December 2021**

The Charity was established in December 2018 and this is the Trustees' third 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 non-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 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 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 three years have greatly exceeded our expectations. Despite many of our planned activities for 2021 being severely curtailed by the Covid-19 pandemic, we still achieved a great deal. The main activities undertaken to further our objectives were –

#### **3.1 Support and Empowerment**

##### Website

The website was upgraded during the year. It 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 343 to 450 during the year. Each day, there are posting 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% would recommend the group to other ALK-positive patients.

##### Surveys

We carried out surveys of our members to ascertain the availability of MRI scans and to assess the prevalence and severity of the side effects of the various prescribed treatments. The data produced enables us to identify variations in the level of services our members receive and regional variations. We use this information at meetings with oncologists and nurses and at conferences.

## Online Activities

Because of the pandemic, we took to Zoom and provided

Seven “ASK THE EXPERT” presentations, available on our YouTube Channel

a weekly exercise session, also available on YouTube

a monthly coffee morning

### **3.2 Advocacy**

In partnership with EGFR+ UK and Ruth Strauss Foundation we launched a £100,000 and award-winning campaign to raise awareness amongst primary healthcare professionals of the need for early diagnosis. The campaign had the support of the British Thoracic Oncology Group, the British Lung Foundation, the Taskforce for Lung Health, Macmillan Cancer Support, Gateway C and the Primary Care Respiratory Society as well as leading Respiratory Consultants and Oncologists.

As a result of our campaign, there were 1.2M impressions across the social media platforms utilised, with 10,000 views of the microsite (our target based on national data for click through rates was 4.3k). Following the campaign in April, we held a UK wide GP training webinar in collaboration with the PCRS (Primary Care Respiratory Society) where non-smoking lung cancer was the topic with several speakers endorsing our messages.

We were also asked to be a panel member for the final Q&A session. Gateway C, the leading UK on-line GP education platform, has developed a module of Non-smoking Lung Cancer as a result of our campaign and we gave them permission to use our assets. We have also shared the campaign with two Cancer Alliance Groups, who were keen to utilise our material in one of their public health campaigns.

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

- UK Advanced Cancers Coalition
- Cancer52
- Genetic Alliance
- International Association for the Study of Lung Cancer
- European Cancer Patient Coalition
- Lung Cancer Europe
- National Council for Voluntary Organisation

We lobbied the DVLA to amend their rules about driving with brain metastases. We formed a DVLA panel and prepared a Frequently Asked Questions document.

We introduced an award for Lung Cancer Nurse Specialists and 36 nurses were nominated by 28 members.

In conjunction with the EGFR+ Group, we published in the medical press a report on the role of UK oncogene-focused patient groups in supporting and educating patients with oncogene driven non-small cell lung cancer.

We submitted an abstract on “The Importance of Support Groups” to the British Thoracic Oncology Group and another abstract on “The Importance and benefits of having a named nurse” at the Lung Cancer Nurse UK Conference.

Our Chair addressed the British Thoracic Oncology Group Conference where she presented the results of some of our surveys, including delays in diagnosis, frequency of scans and treatment of bone metastases. She also addressed the Women Against Lung Cancer in Europe Conference where she shared examples of the work ALK Positive UK has done to support patients across the UK.

We regularly posted on Twitter.

### **3.3 Fundraising**

Despite the restrictions of the pandemic, our members undertook a wide range of activities which, together with those activities organised by the charity, raised £38,000. One of our fundraisers said “I was diagnosed with Stage 4 ALK-positive lung cancer a few weeks before my 40th birthday. The ALK Positive support group has inspirational and amazing members who provide invaluable advice and are a great source of knowledge and comfort. Having been reasonably active throughout my life, I decided to take part in a challenge every 6 months to raise awareness that anyone with lungs can get lung cancer”

## **4. Financial Review**

The Charity had £112,121 in its bank account at the end of the year, including £37,942 of restricted funds. This was a year-on-year increase of 56,843 due, on the one hand, to a sharp reduction in our expenditure resulting from having to cancel some of our planned activities and, on the other hand, our income holding up as a result of successful fundraising events.

We do not occupy premises and we do not 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

## 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	164 Guildford Road Lightwater Surrey GU18 5RL

## 7. Names of the Charity Trustees who Managed the Charity in 2021

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			
Angela Field			
Tessa Rust		From 4 April 2021	
Lynne Murtha		From 4 April 2021	
Catherine Gibbard		From 4 April 2021	

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	<i>G H Lavender</i>	<i>D L Montague</i>
Full Names	Graham Herbert Lavender	Debra Louise Montague
Positions	Treasurer	Chair
Date	19 <sup>th</sup> April 2022	19 <sup>th</sup> April 2022

## Income & Expenditure 2021

### Income

Opening Balance		55,279
Donations	4,391	
Grant (Conference)	11,850	
Sale of goods	48	
Gift Aid	975	
Fees Charged	3,608	
In Mem	2,940	
Amazon + easyfunding	314	
Our Fundraising Events	17,053	
Private Funraising	21,237	
Early Diagnosis Campaign	101,942	
Other	58	
		164,415
		219,694

### Expenditure

Patient Materials & Postage	3,962	
Website	444	
Trustee Expenses	57	
Events	2,149	
Fitness classes	2,305	
Q&A Sessions	4,200	
Early Diagnosis Campaign	91,145	
Nurse Awards	228	
Just Giving	187	
Admin	2,423	
Other	473	
		107,572
Closing Balance		112,121
Restricted		37,942
Unrestricted Balance		74,179



Section A

Independent Examiner's Report

Report to the trustees/  
members of

Charity name  
ALK Positive Lung Cancer (UK)

On accounts for the year  
ended

31/12/21

Charity no  
(if any)

1181171

Set out on pages

1 & 2

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31/12/21

Responsibilities and  
basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent  
examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Signed:

Date:

24/07/22

Name:

Andrew Evans

Relevant professional  
qualification(s) or body  
(if any):

Address:

4 Curley Hill Road, Lightwater, GU18 5YG



Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.