

ALK POSITIVE LUNG CANCER (UK)

Charity No. 1181171

TRUSTEES' ANNUAL REPORT

1 January 2020 to 31 December 2020

The Charity was established in December 2018 and this is the Trustees' second 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 so as 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. 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, 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 two years have greatly exceeded our expectations. Despite many of our planned activities for 2020 being severely curtailed by the Covid-19 pandemic, we still achieved a great deal. The main activities undertaken to further our objectives were –

2.1 Support of Patients

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.

Facebook Page

The Facebook page is a great success and the number of users increased from 245 to 343 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.

Patients' Forum

Eighty members attended the Forum meeting in London where they heard presentations from ALK+ expert and were able to ask questions.

Publications

We published "Good Practice from the Patients' Perspective" and this was endorsed by three leading ALK+ experts.

We also published "Living with ALK+ Lung Cancer" which contains valuable information for patients and their families.

Online Activities

Because of the pandemic, we took to Zoom and provided

a weekly diet club

a monthly Alkie Arms – informal meeting with a glass in the hand

a weekly exercise session

a monthly coffee morning

2.2 Advocacy

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. These meeting were in person in the first quarter of the year and then online thereafter. 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.

An Abstract about our MRI data was accepted by the International Association for the Study of Lung Cancer for their annual conference in Singapore.

We contributed to Lung Cancer Europe's report on the Psychological and Social Impact of Lung Cancer and to Roy Castle Foundation's "I'm Still Here" campaign

We conducted a major survey of members to ascertain information about their treatment. The data obtained will inform our advocacy at meetings with health care professionals.

2.3 Fundraising

We participated in Cancer52's 20for20 fundraising event. 35 of our members took part and over £15,000 was raised.

We received a grant of £11,850 for half the cost of our planned Patients' Weekend Conference and a grant of £7,000 towards Breathe For Life's End to End cycle ride.

3. Financial Review

The Charity had £55,279 in its bank account at the end of the year, including £11,850 of restricted funds. This was a year-on-year increase of £32,553 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 the successful 20for20 fundraising event.

We do not have premises and we do not employ staff. 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.

4. 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 and there were five throughout 2020.

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

5. Reference and Administrative Details

Charity Name	ALK Positive Lung Cancer (UK)
Other name the charity uses	ALK+ UK
Registered charity number	1181171
Charity's principal address	164 Guildford Road Lightwater Surrey GU18 5RL

6. Names of the Charity Trustees who Managed the Charity in 2020

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	Communications		
Susan Eastwood	Research		
Angela Field	Fundraising		

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

7. 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	Treasurer	Chair
Date		

Income & Expenditure 2020

Income	2020
Opening Balance	22,726
Donations	4,611
Grant (Takeda) Patients Forum	11,850
Grant (Takeda) End2End cycle ride	7,011
Sale of goods	457
Gift Aid	2,363
Forum registrations	840
Fees (Deb's appearance payments)	2,185
In Mem	8,975
20four20 fundraising	13,232
Abseil registration	600
Amazon	176
Our Fundraising Events	2,453
Private Funraising	1,360
Other	
	56,113
	78,839
Expenditure	
Merchandise	557
Patient Materials & Postage	4,874
Patient Forums	3,250
Printing & Publicity	1,276
Website	3,992
Trustee Expenses	0
Events	8,836
Fitness classes	650
Other	125
	23,560
Closing Balance	55,279
Restricted (Takeda Forum grant)	11,850
Unrestricted Balance	43,429

Independent examiner's report on the accounts

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**

31/12/20

**Charity no
(if any)**

1181171

Set out on pages

1 and 2

(remember to include the page numbers of additional sheets)

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended DD / MM / YYYY.

**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.

** Please delete the words in the brackets if they do not apply.*

Signed:

Andrew Evans

Date:

9 August 2021

Name:

Andrew Evans

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

Address:

4 Curleyhill Road, Lightwater GU18 5YG

Section B**Disclosure**

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.

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