

Extract of Trustees' Annual report for 2020

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.