

TALK

POSITIVE

SUPPORTING PATIENTS WITH ALK POSITIVE LUNG CANCER

ISSUE 02 • February 2021



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Anyone with lungs can get lung cancer

THANK YOU to all of our amazing 20 for 20 participants!

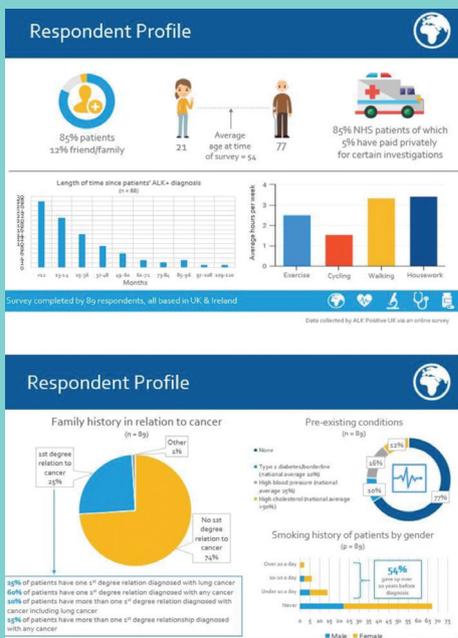
Our aim from the outset has been to support patients



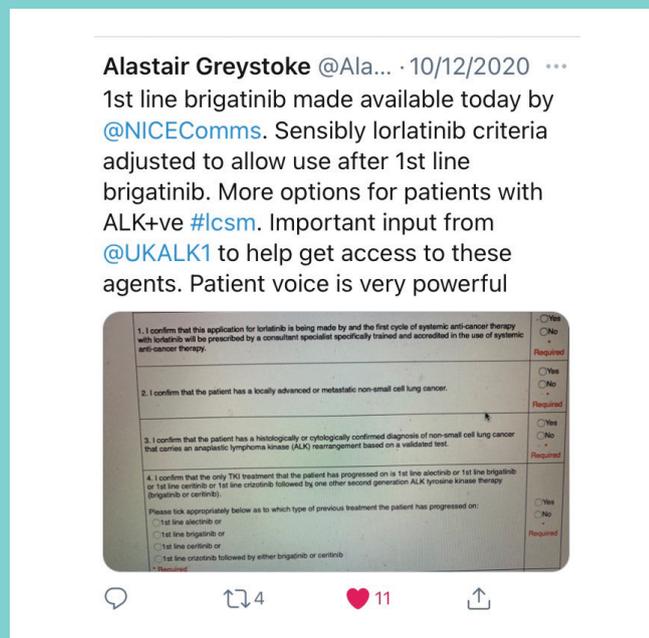
Our Facebook page provides a platform where patients, families and friends can offer and receive mutual support.

Our website provides information about the charity and ALK-positive lung cancer.

Advocacy on behalf of patients



We strive to project a high profile at conferences attended by lung cancer oncologists and nurses, where we display abstracts showing our activities.



We make extensive use of all social media to get awareness of our messages. Here we have recognition from a leading ALK+ consultant of our contribution in support of the application to NICE for the approval of Brigatinib.

A welcome from our founder **Debra Montague**



Welcome to our second Newsletter, an update on some of the activities of ALK Positive Lung Cancer (UK) in 2020.

We started the year with ambitious plans, including:

A weekend Conference (Patient Forum). Funding was in place from two pharmaceutical companies, the hotel was booked, and six leading ALK-positive experts were lined up to speak

Abseil down Mittal Orbit in London

Kensington Gardens Walk

Attending and displaying at the British Thoracic Oncology Group annual conference of 2000 thoracic oncologists

Encouraging members who live reasonably close to each other to get together for coffee or lunch

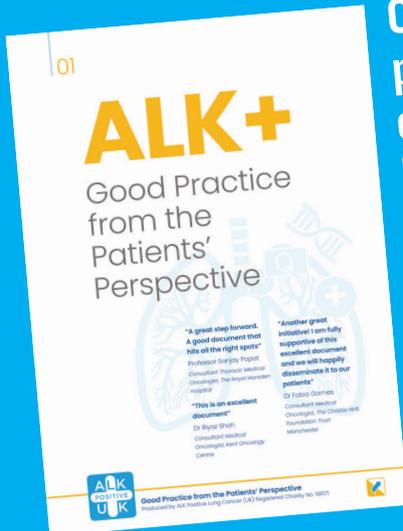
Attending and displaying at the Lung Cancer Nursing UK annual conference of 800 lung cancer nurse specialists

Attending and presenting at regional meetings of lung cancer nurse specialists and Macmillan nurses

Royal Parks Half Marathon

But, in the words of Robert Burns "The best laid schemes o' mice an' men gang aft a-gley". The unforeseen COVID 19 pandemic came along and none of these activities were possible.

However, we are very pleased to report that there were other activities in our plans that we did achieve.

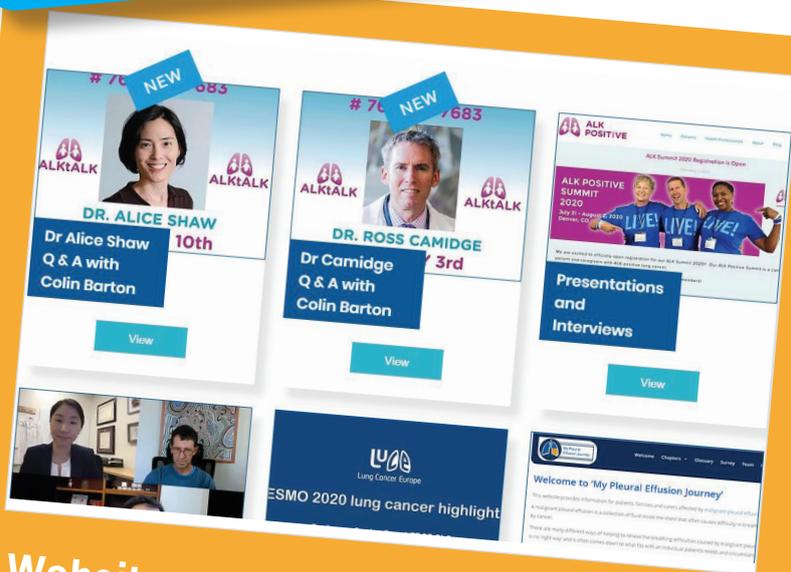


Creation and publication of 'Good Practice from the Patients' Perspective', endorsed by three leading ALK+ oncologists -

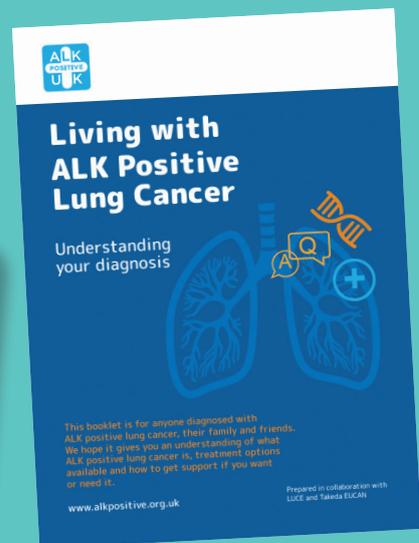
can be viewed on the website with hard copies available on request



A Patient Forum in London in February attended by eighty members. Notes of this meeting are available on our website



Website upgraded – and now packed with even more useful information, including videos of presentations by world-renowned experts



Creation and publication of a Patients Booklet - can be viewed on the website with hard copies available on request

We were concerned that during the prolonged pandemic, some members would be experiencing feelings of isolation and, as with many other organisations, we turned to Zoom to keep in contact. We now offer:

A weekly slimming club - very laid back, no pressure, we talk about meals and exercise

A monthly ALKie Arms - informal evening chat with a glass of whatever tickles your fancy in the hand

A weekly exercise session



A monthly coffee morning - no agenda, we just let the conversation and discussion lead us

As in most years, some activities cropped up that were not planned at the start of the year.

Paul Cooper and Michael Stenton were interested in challenging the DVLA about their rules concerning loss of driving licence when a brain metastasis is diagnosed. We put together a survey of members to gather information about the incidence of brain mets and seizures. The survey was expanded to include UK EGFR patients and world-wide ALK+ patients. The results of the survey supported Paul's and Mike's contention that the DVLA rules are unreasonably restrictive for ALK + patients and the Charity has made a submission to the DVLA to request that they commission a review of the rules by leading ALK+ consultants. We have also lobbied the Department of Transport and individual members have lobbied their Members of Parliament.

The Charity is a member of several national and European organisations that are focused on rare diseases or lung cancer. One of these groups, Cancer52,

was concerned about the loss of income that charities were experiencing during the pandemic and organised the **20 for20** fundraising event. We are very grateful to 35 of our members and friends who participated, raising £15,000 for the Charity. Photographs of some of the participants are featured on front the cover.

We continue to make representations to the National Institute for Health Care Excellence (NICE) in respect of any applications for approval of ALK+ medications.

Over 100 new members have joined the Facebook group this year. The feedback we get is that members benefit enormously from the information and support they receive from fellow patients. We celebrate good news but find it hard to deal with sadder bad news.

An Abstract about our MRI data has been 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 the Roy Castle Foundation's "I'm still here" campaign.

Looking forward to 2021

We were particularly disappointed that the weekend conference planned for September last year was lost. We have held five Patient Forums and they have been attended by an increasing number of members.

They provide an opportunity to listen to, and question, leading ALK+ oncologists and to exchange experiences of treatments, side effects, etc.

However, we have rescheduled the conference for Birmingham starting on 17 September this year, subject of course, to the Covid-19 situation. The conference will be funded by Takeda and Roche and will be free to our members accompanied by one other person including travelling costs. We will arrive on Friday afternoon and depart

on Sunday afternoon and there will be a full programme of presentation by ALK+ experts.

Towards the end of last year, we worked with the EGFR Group on preparing an Early Diagnosis campaign to increase the awareness of GPs to the increasing prevalence of lung cancer in younger non-smokers. Jenny Abbott of the EGFR Group has taken the lead on this and has been instrumental in obtaining over £300,000 of pro bona consultancy work, including photographs by Rankin. We are grateful to Faye Wrotchford, Cameron Millar, Debbie Gardener and Amelia Greenwood-Clark for taking part in the campaign which we plan to launch early in the year.

We are looking into the possibility of holding an **online Q&A session** with one or two world-leading oncologists.

We are going to offer **online group support** run by clinical psychologists.

Last year, we conducted a joint membership survey with the EGFR Group and the results of that survey are going to appear in the Journal of Oncology and Therapy.



Sincere thanks to Faye Wrotchford, Debbie Gardener, Cameron Millar and Amelia Greenwood-Clark.



Our plans for the year include the postponed activities of an abseil down Mittal Orbit, a wing walk, sponsoring runners in the Royal Parks Half Marathon and a Kensington Gardens Walk.

But, at the time of preparing this Newsletter, we are in the darkest hours of the Covid-19 pandemic. Vaccinations will be our saviour, but we, like everyone else, don't know to what degree of normality we will return.

We hope that you found this an interesting update of our activities for the Charity over the past year.

We would like to thank all our members who contribute to the Facebook group. It is the mutual support we give each other that is at the heart of our ethos and that produces the feeling of an ALK+ family. And thank you to all those who took part in or contributed to fundraising activities - **without your support, we could not achieve everything that we do.**

Despite last year being unprecedentedly difficult, we strove to support patients with ALK+ lung cancer, their families and friends and to advocate on their behalf.

Last year, we made a promise never to lose our focus of support and advocacy and I am happy to repeat that promise again.

Deb xx

Debra Montague

On behalf of ALK Positive Lung Cancer (UK)





Changing perceptions of lung cancer together Advocacy on behalf of patients

Raising awareness of the charity
and support group

Encourage Oncologists and LC Nurses
to direct their ALK+ Patients to us

Raising awareness of what we are doing for
ALK+ Patients and how we can help research
and medical professionals in the future

To find out more and to download your
fundraising pack visit

www.alkpositive.org.uk
hello@alkpositive.org.uk