

TALK



POSITIVE

SUPPORTING PATIENTS WITH ALK POSITIVE LUNG CANCER

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IN THIS ISSUE:

- ◆ A welcome from Debs
- ◆ Our aims
- ◆ Our achievements
- ◆ Patient forum update
- ◆ Patient map
- ◆ 2020 plans



Anyone with lungs
can get lung cancer



One year on!

Our aim from the outset has been to support patients



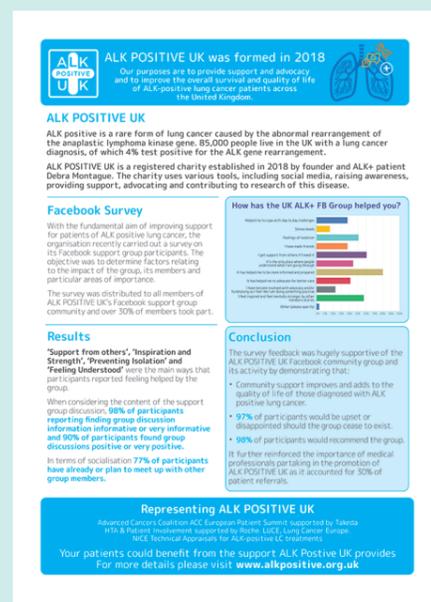
Our Facebook page provides a platform where patients, families and friends can offer and receive mutual support.

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

Advocacy on behalf of patients



Raising awareness of ALK-positive lung cancer amongst the medical profession so as to promote best treatment.



Influencing decision-makers, eg NHS, DVLA and NICE and liaising with other relevant organisations.

A welcome from our founder **Debra Montague**



Some of us, when first diagnosed, joined the USA-based world-wide ALK Positive Facebook site. But, we soon realised that we needed a separate UK group that could address UK-specific issues, e.g. NHS, DVLA and NICE.

18 ALK patients and supporters met in London in July 2018. We were addressed by Professor Sanjay Popat, a leading ALK-positive expert, who strongly supported the establishment of a UK group. Our Facebook page was launched the same month. The second meeting was held in Manchester and it was decided that we should seek registration as a Charity. We launched our website in November and Charity registration was achieved in December.

So, what have we been up to in our first year? Where do we start as we have achieved so much?

Firstly, we have grown from 90 to 245 members in just 12 months. This is great news as the feedback is that you love the support group, so now more of us are benefiting from it. We still have a way to go before every ALK-positive patient has heard about us. We will achieve this in two ways -

- 1. Each of us need to keep the support group in the forefront of our Oncs' and nurses' minds** by providing them with a steady supply of our leaflets.

- 2. Attending key conferences.** We will be attending the British Thoracic Oncology Group in January along with the Lung Cancer Nurse UK conference in November again in 2020 and exploring the value of attending further events.

We have had an amazing year for friends, family and members fundraising - £45,000 has been raised in total through a breadth of events, some more hair-raising than others - I am thinking of our 76 year-old treasurer wing walking along with Marion James and Kim Grant. I hope to do this in April or May - anyone fancy joining me?

We launched the Walk4ALK event at the beginning of lung cancer awareness month and over 80 members and family/friends walked around Kensington Gardens and raised a very impressive £3,600 - can we make this 100 people this year?

We will have several events this year for anyone to sign up to - some more and some less energetic, so there will be something for everyone!

Finally, I would also like to take this opportunity to thank everyone for being active in the support group - it only works if members offer support when someone puts a post up, so thank you everyone for looking out for each other. It really does feel like a second family to me!

I can't wait to see us continue to celebrate the good times and be supportive during the not so good times. We all have good and bad days and we can definitely help each other remember to put our big boy or girl pants on after a bad day.

I hope to see you all in 2020

Best wishes Debs x

Our achievements in the last year

500%
increase in membership
since start of the group

Succeeded in persuading
Pfizer to keep open their
compassionate programme
for Lorlatinib

Secured a grant of £7,000
to go towards the cost of
organising the Breathe4Life
cycle challenge

Held two Patient Forums each attended by over 50 patients and family/friends in London and Birmingham. Both forums were addressed by leading ALK positive experts. Travel grants were offered



September 2019, Birmingham
20 patients and 22 carers attended and received talks from; Debra Montague, Dr Rohat Lal from Guy's Cancer Centre and Sinead Cope the head of Maggie's Centre. Attendees also took part in a 2 hour open forum when patients shared experiences and support.



February 2019, London
28 patients and 24 carers attended and received talks from; Debra Montague, Dr Shobhit Baijal, a consultant oncologist from Birmingham Heartlands Hospital and Dr Rob Hurry, a GP. Attendees were also informed of the NICE assessment process and an open forum was held.

Raised awareness of the Charity by attendance at the British Thoracic Oncology Group (BTOG) Annual Conference attended by around 900 delegates, the Lung Cancer Nurses UK Annual Conference attended by 350 delegates and the 6th Royal Marsden Lung Cancer Symposium attended by 200 delegates



The ROYAL MARSDEN
NHS Foundation Trust



Produced various
merchandise
for sale

£12,000
raised at a Sky
Dive event

Secured a grant of
£15,000 from Macmillan
to redesign the website and
produce publicity material

Consulted by Takeda on
the wording of their patient
leaflet for Brigatinib

Produced a leaflet on
brain mets and DVLA

Recognised by NICE and its Scottish
equivalent (SMC) as the organisation
representing ALK Positive patients in the UK.
Submitting evidence to both organisations on
the Lorlatinib applications

Offered travel grants for
patients seeking second opinions

ALK POSITIVE UK
Our mission is to provide support and information to patients and carers with ALK positive lung cancer in the United Kingdom.

Facebook Survey
With the introduction of a new form of lung cancer (caused by the abnormal rearrangement of the anaplastic lymphoma kinase gene, ALK) in the UK with a lung cancer diagnosis, of which 4% test positive for the ALK gene rearrangement, ALK POSITIVE UK is an emotional charity established in 2018 by founder and ALK patient Debra Montague. The charity uses various tools, including social media, raising awareness, providing support, advocating and contributing to research of this disease.

How has the UK ALK+ FB group helped you?

Kept me up to date on the latest news	87%
Kept me up to date on the latest research	87%
Kept me up to date on the latest clinical trials	87%
Kept me up to date on the latest support services	87%
Kept me up to date on the latest patient stories	87%
Kept me up to date on the latest patient experiences	87%
Kept me up to date on the latest patient advice	87%
Kept me up to date on the latest patient information	87%
Kept me up to date on the latest patient resources	87%
Kept me up to date on the latest patient support	87%
Kept me up to date on the latest patient help	87%

Conclusion
The survey feedback has helped support of the ALK POSITIVE UK Facebook support group and its ability to disseminate support and advice to the ALK POSITIVE UK community. The survey also highlighted the need for support and advice to be available in other languages and to be available in other formats (e.g. audio, video, etc.).

Representing ALK POSITIVE UK
ALK POSITIVE UK is a registered charity (1170808) and a limited liability company (1170808) in England and Wales. The company is a subsidiary of ALK POSITIVE UK (UK) Limited, a subsidiary of ALK POSITIVE UK (USA) Inc. For more details please visit www.alkpositive.org.uk

Shortlisted by BTOG for their poster Award

Introduced a location map for all UK patients

Fully-funded residential weekend Patient Forum in Stratford-upon-Avon in September being planned

Carried out a comprehensive survey of ALK patients (report being prepared)

Held a Walk4ALK event in Kensington Park attended by 88 people

What will 2020 bring?

Add your location to the ALK-positive patient and friends map



Being an ALK+ patient can be a lonely experience but meeting other ALK patients to exchange experiences can be very rewarding

Last year, a number of patients arranged lunches/coffee mornings for fellow Alkies living close by. This year, we intend to encourage more of these local meet-ups. It would be very helpful if all members of our group could add their locations to the map.

Have you added your location to our map of ALK-positive patients and friends? If not, please go to:

https://www.zeemaps.com/map?group=3572664&fbclid=IwAR0Bt1oBZH-k248DkyP-zPooz4ewZ7fMqANUEoKkyoujHzaSpZjeL-wX_uDg



Walk4ALK warm up!

Pushing forward into 2020

JANUARY
7th Lorlatinib NICE review
29th- 31st BTOG conference

FEBRUARY
4th World Cancer Day
22nd Patient Forum London
ALK+ board meeting

MARCH
Launch of new ALK+ UK website
Release of questionnaire results
Presentation to Cancer Research
Launch of UK patient handbook

I hope that you found this Newsletter informative. It is quite long as it covers the 18 months since the group was formed. We hope to produce future newsletters at regular intervals.

Our achievements in the first year have greatly exceeded my wildest expectations and I want to thank everyone who has:

- ◆ Posted supportive comments
- ◆ Donated or taken part in fundraising
- ◆ Given freely of their time, particularly the Board of Trustees and our Advisers
- ◆ Completed our comprehensive survey
- ◆ Placed their location on our map

We have received encouraging feedback, not only from our members but also from other organisations with whom we are working. Recent comments received from these organisations include, "you are punching above your weight" and "you have a reputation for getting things done".

Finally, I conclude with our promise – **we will never lose our focus, providing support to ALK-positive patients throughout the 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

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