

# TALK



POSITIVE

SUPPORTING PATIENTS WITH ALK POSITIVE LUNG CANCER

ISSUE 03 • March 2022



Stage 4 and Loving Life



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Anyone with lungs can get lung cancer

SUPPORT • EMPOWER • ADVOCATE



## Welcome From Debs

Welcome to our third annual Newsletter in which we record some of our activities in 2021. Of course, COVID-19 again caused us to cancel many of our planned events:

- No weekend conference
- No Patient Forums
- No local get-togethers
- No attendance at conference

However, we made the best out of a bad situation, and we achieved a great deal despite being socially distanced or locked down. I continue to be heartened by the support offered in our FB group. The success of this group is down to each member who posts or responds to someone's comment, question, or concern. I am incredibly proud of this group and hope that members will continue to support each other as we are all in the same boat.

I was really pleased that we were able to translate our leaflets into 6 additional languages that are commonly spoken across the UK. We have also introduced a translation facility on the website.

I hope that you find this newsletter interesting as we have tried to capture some of the highlights of the previous year and give you an insight into our plans for the current year.

In conjunction with the EGFR Group, we published in the medical press a report on the role of UK oncogene-focussed patient groups in supporting and educating patients with oncogene driven NSCLC.

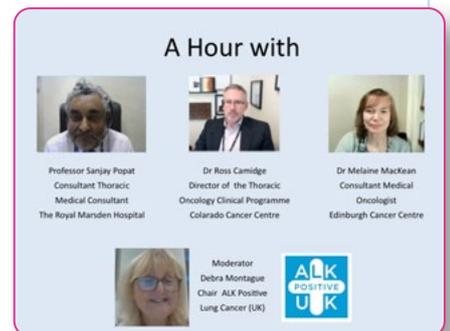


## Ask the Expert

We held seven ASK THE EXPERT sessions where we invited experts on various topics to talk to us - about treatments, exercise, mental health, etc. - and we were then able to ask them questions.

We had several leading ALK-positive experts from around the country speak to us - Dr Greystoke from Newcastle, Dr Shobhit Bajjal from Birmingham, Dr Newsom-Davis from London and the most famous of all, two leading ALK-positive experts from both sides of the pond - Professor Ross Camidge from the USA and Professor Sanjay Popat from The Royal Marsden.

If you missed any of these sessions, you can find a link to our YouTube channel on the Resources page of our website. If you saw them the first-time round, you may still like to revisit them.



## Well, this was a first for the charity - a proposal at the top of the London Orbital

'Friends of ALK' member John decided that the ALK Abseil would be the best time to ask his partner to marry him. I suppose he thought there was less chance of her saying no as she teetered on the edge of a 300M drop. Well, his plan worked, and our Chair is now going to be Matron of Honour at their wedding in October. I am sure I can say on behalf of everyone who met the lovely couple on the day - congratulations and all the best for the big day.

The event was a great success, everyone had a great time and to cap it all £7,000 was raised. ■



# Some of our 2021 highlights



Zoom again came to the rescue and we continued with our fitness classes and coffee mornings.



We continued to develop our website and added new information to our Resources and Reports pages. We have also redesigned the home page of the website to emphasise our principal purposes of **supporting, empowering** and **advocating**, so that our members enjoy the best life possible for as long as possible.



We have formed a DVLA panel, comprising Paul Cooper, Ian Cluett and Duncan Edmonstone. We are very grateful to them for preparing a Frequently Asked Questions document which is now on the website and for submitting a comprehensive Freedom of Information request to the DVLA.



Our map continues to get busier with many additions from new members. If you haven't already added your location to the map, you might like to do so.

# British Lung Foundation Backed new Lung Cancer Campaign urging GP's to 'See Through The Symptoms'

Many of you will remember we launched our **Early Diagnosis Campaign: See Through the Symptoms** in April 2021. This was in partnership with EGFR Positive UK and the Ruth Strauss Foundation. The See Through the Symptoms campaign, targeted GP's and other Primary Healthcare Professionals and featured four of our members - Amelia, Cameron, Debbie and Faye. For all of them diagnosis took many months. The photographs for the campaign were taken by the world-renowned British photographer Rankin (who lost his mother

to lung cancer in 2005). I believe he made all our members very welcome, and I can't believe Cameron came away with this photo as a souvenir! What a lucky boy!



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. We raised over £100,000 to deliver this campaign.

**Prof. Sanjay Popat**, Consultant Thoracic Medical Oncologist at the Royal Marsden Hospital said:

I'm pleased to see the launch of this campaign. I see too many patients who have never smoked present with late-stage lung cancers. It is really important that we raise awareness amongst all healthcare professionals, that people who never smoked can get lung cancer too.

**Dr Sam Hare**, Consultant Chest Radiologist and a lung cancer expert for the British Society of Thoracic Imaging (BSTI) said:

It remains crucial to remain vigilant to the possibility of lung cancer in non and never-smokers, particularly adenocarcinoma which can occur due to genetic mutations. Early diagnosis with imaging such as CXR and low dose CT is pivotal to good outcomes and cure.

**To view the microsite all GP's and Primary Healthcare Professionals were encouraged to visit [www.lungcancerseethroughthesymptoms.uk](http://www.lungcancerseethroughthesymptoms.uk) You will also be able to view the 'adverts' featuring our members here.**

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 as one of their public health campaigns

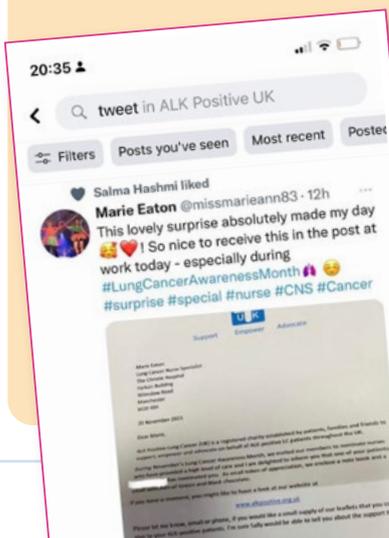


for 2022 which they promote to all GP's and practices across their geography. The Royal Marsden magazine also ran an article on the campaign. We re-ran the campaign in November with another 1.4M impressions.

We intend reviewing the campaign in 2022 and exploring how we might utilise all or some of the assets as there are still GP's who need to be reminded that anyone with lungs can get lung cancer. ■

## Recognising our Nurses

We introduced an award for Lung Cancer Nurse Specialists and 36 nurses were nominated by 28 members. We sent all the nominees a small box of chocolates, a notebook and a letter outlining why they had been nominated to receive their award from ALK Positive UK. As many people thought this was a good idea, we will continue this and will send next year's Awards out during Nurses Week 6 -12th May. It's never too early to get your nominations in. ■



## Keep in touch

Relying on Facebook to communicate with our members is not very efficient. We are, therefore, moving towards direct emailing to members.

If any member of the Group has not been receiving emails, it's probably because we don't have their email address. Please email us at [hello@alkpositive.org.uk](mailto:hello@alkpositive.org.uk) if you would like to be added to our mailing list. ■

## Thank you for your time

We are very grateful to all those members who completed our surveys. 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. This year was no different as we submitted an abstract on 'The Importance of Support Group's' at 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.

I was honored to be asked to speak at BTOG where I presented the results of some of our surveys including delays in diagnosis, frequency of scans and treatment of bone mets.

I was also asked to speak at the Women Against Lung Cancer in Europe Conference where I was asked to share examples of the work ALK Positive UK has done to support patients across the UK. ■

# ALK Fundraiser Wall of Fame

Although we were unable to arrange any large fundraising events, some of our members were incredibly active and raised lots of money, which will be put to good use. The photographs of all our fundraisers can be seen in our website Hall of Fame and we are very grateful to each one of them. Here's a selection of just a few.....



Jenny

"We created #WellerFest to help raise funds for and awareness of ALK Positive UK. As a young, fit and athletic personal trainer, I had no idea my long-term cough was a symptom of cancer. We need to tell the world that anyone with lungs can get lung cancer and I'm enjoying the adventures we're having along the way. In 2021, we abseiled, triathloned, sea swam and trained hard. In 2022, we will cycle from John o' Groats to Lands' End, climb Mount Snowdon and Zip across Penrhyn Quarry."



George

"Learning that my young friend, Faye, was unfortunate enough to contract such a brutal and unfair form of cancer was desperately upsetting. Her bravery and positivity in the face of the disease has been incredibly inspiring and really made me want to do something. Hearing about and seeing the excellent work that ALK Positive UK has done to support Faye, made it very easy for me to want to help, however I could. A bit of running from me feels like nothing compared to what others do but I'm glad I can contribute in some way."



Scott

"In February 2021, my wife Sarah went to the GP for antibiotics to treat her persistent cough. Two weeks later, we were given the devastating news that she had stage 4 cancer. In the whirlwind of emotions that followed in the days shortly after, she was eventually diagnosed with a rare form of lung cancer called ALK positive which, though still incurable, was now at least treatable and gave her hope of relative health for a few years. During those early days and still now a year later, the support and advice given by the online community of the charity ALK positive UK was vital to us as a family so I decided that the least I could do was to try and raise some funds by running a half marathon. 2022 has come round quickly and Sarah is responding well to her targeted treatment and I am planning my next fundraiser!"



## Leanne

"My husband, Drew, died suddenly last March. My world was turned upside down. In January, 2021, I had committed myself

to running 1,000 miles to raise money for ALK Positive UK. I decided to go back to my challenge in April and completed my 1,000 miles in November. I was so sad that Drew wasn't there but he was, because I carry him in my heart. I want to express my gratitude for the overwhelming amount of messages I received regarding Drew. The outpouring of love for Drew, myself and the girls was a great comfort to me at a difficult time."



## Aaron

"In 2014, my mum, Angela, was diagnosed with ALK+ lung cancer. She was 39 years old, had never smoked and had run a marathon the year before. I was

8, and had no idea what that diagnosis meant. However as an older me found out, doctors had advised my mum to go on holiday with the family and had said it could have been her last.

Even now 8 years later, her cancer cells have not gone away and she has to take 11 pills every day. I decided to fundraise for ALK+ UK because I'm so proud of my mum. She doesn't let anything stop her and has even run the London Marathon twice since her diagnosis. The London Revolution was my first charitable sporting event and I hope to challenge myself with many more."



## Joey

My partner's father was diagnosed with ALK+ lung cancer just over 2 years ago. He is a wonderful

human being and, seeing his positive attitude in the face of what he's had to deal with, made me want to raise money and support the charity that supports him. I'm far from an athlete myself, so I thought a good challenge would be to run 12 marathons in 12 months. Although hard, I was determined to do it to show my support for him and all others suffering from the condition. After 12 gruelling months, I was not only fitter but I'd managed to support the ALK+ UK charity. I'm so grateful for the support I received while undertaking this challenge and I'm so proud to have been a small part of his journey and in helping others by supporting the charity.



## Sush

"I was diagnosed with Stage 4 ALK Positive lung cancer 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 and funds for my ALK+ family."

# To the Future and ALK Positive UK in 2022

Despite the restrictions caused by COVID-19, we are extremely proud of the Charity's achievements in 2021 and very grateful for the support of all members. We will continue to support patients, their families, and friends; to empower them to ensure that they get a high level of care; to advocate on their behalf with healthcare professionals to ensure that this high level of care is delivered throughout the UK.

## Our plans for 2022 include -

- ◆ With the appointment of Carol Wickes as our Events Manager, you can look forward to several social events across the year. You will hear more from Carol over the coming weeks, and I hope many of you will be able to join us. I always love meeting new members and catching up with old friends - it's the best part of the job.
- ◆ Major digital campaign to raise the awareness of lung cancer oncologists and nurses of the benefits their new patients can gain from joining our group. We have been working behind the scenes with an experienced communications agency to develop our communication strategy for the next 12 - 18mths.
- ◆ A Counselling Service for UK ALK Positive patients and their immediate families, including children. We are currently talking with providers and hope to have something in place by the end of the year.



## ALK Positive Lung Cancer (UK)

### 1st Patient Conference

First opportunity for over two years to meet fellow ALKIES



Key Note Speaker  
Professor Sanjay Popat

23 – 25 September 2022

Strathallan Hotel | Birmingham

- ◆ Having had two years of postponements we are excited that our weekend conference in September for patients plus one other at no cost will finally be taking place. Expert speakers and plenty of time to socialise with other members. We now have 7 speakers confirmed for our weekend away, so we should all learn something new whilst having time to meet and socialise with other ALK-positive members. I am certainly looking forward to welcoming everyone at the drinks reception on the Friday evening.

It just leaves me to say thank you to everyone who supports us, and I look forward to hopefully meeting up with many of you throughout the year.

Best wishes ~ Deb x



ALK Positive Lung Cancer (UK)

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