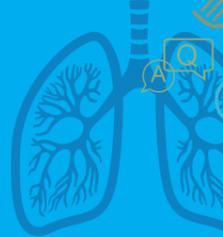


**Helping**  
 ALK-positive  
 lung cancer  
 patients **live** their  
**best lives** for as  
**long as possible**



# Support. Empower. Advocate.



## Who we are



ALK-positive lung cancer is a rare form of non-small cell lung cancer caused by the abnormal rearrangement of the anaplastic lymphoma kinase gene. Diagnosis is not linked to genetics, age, gender, smoking status, or pre-existing health conditions. In fact, most patients have never smoked, and around half are under 50 when diagnosed, some even younger. Approximately 1,600 people are diagnosed with ALK-positive lung cancer in the UK every year, of which the majority are diagnosed at stage 4.

We are recognised by NICE (National Institute for Health and Care Excellence) as an organisation to be consulted on new ALK-positive treatments.

ALK Positive Lung Cancer (UK) was founded by patient Debra Montague. Today, Debra is assisted by a close-knit team of trustees, advisors and business experts.



Debra Montague  
Founder & Chairwoman

### + Did you know?

We have presented independent research, on the treatment of our members, at multiple national and international conferences and co-launched a national symptoms awareness campaign.

Today, ALK Positive Lung Cancer (UK) provides an invaluable platform where patients and their families can exchange information about their diagnoses and treatments, and where they can give and receive mutual support.

The charity is a primary source of information, to inform and empower patients about their disease, available treatments, and best-practice disease management.

We advocate on behalf of ALK-positive patients to ensure that they receive the highest level of care, whatever their demographic, and wherever they live in the UK.



Graham Lavender  
Finance & Administration



Rebecca Stebbings  
Communications Lead



Angela Field  
Trustee



Professor Susan Eastwood  
Board Member



Lynne Murtha  
Board Member



Paula Tulley  
Board Member

### + Did you know?

Lung cancer in never-smokers is now the UK's 8th most common cause of cancer-related death, causing nearly 6,000 deaths a year<sup>1</sup>.

Introducing ALK Positive Lung Cancer (UK) – a vibrant, active and determined community dedicated to helping every person diagnosed with this rare, currently incurable, cancer to receive the best care possible, and live their best life for as long as possible.

The charity has one fundamental goal: to extend the overall survival and quality of life of ALK-positive lung cancer patients across the UK.

ALK Positive Lung Cancer was established in 2018 by patients, their families, and friends. Our journey began as a social media patient support group and we have grown to become a well-respected and trusted source of ALK-positive lung cancer information.

Receiving any cancer diagnosis is overwhelming to say the absolute least. Learning you have a rare cancer that many HCPs have little awareness of creates a whole other dimension of despair and powerlessness. If we can support and empower just one newly diagnosed patient and advocate for them in the medical sector, we will have been successful in our mission

Debra Montague, Founder and Chairwoman of ALK Positive Lung Cancer (UK)

The charity's trustees are supported by a team of creative, marketing, fundraising, communications, social media and events experts who collaborate to produce materials, events and resources that enable the charity to fulfil its goals and ambitions. Further to this, a dedicated DVLA panel assists in the complex navigation of the DVLA system for cancer patients who develop brain metastases.

Together, this 18-strong team, backed by each and every member and supporter of the charity, contributes to the charity's growing success on a daily basis.

You can learn more about the team behind ALK Positive Lung Cancer (UK) on our website.

<sup>1</sup>Lung cancer in never smokers: a hidden disease (2019). The Royal Society of Medicine.

# What we have achieved

ALK Positive Lung Cancer (UK) has achieved so much in just four years, and we could not be more proud. From humble beginnings to opinion leadership status in the field of ALK-positive lung cancer, our charity continues to break boundaries and deliver inspiring results for patients.

## Patient & HCP Resources

Prior to 2018, no specific resources existed to provide information, support or advice for UK patients or HCPs regarding any part of the lung cancer journey. Today, ALK Positive Lung Cancer (UK)'s comprehensive library of resources gives incredible insight and research-driven information on this rare NSCLC to improve quality of life and overall survival outcomes. With the support of our medical and marketing experts, booklets, infographics, presentations, videos and handouts are freely available and can be accessed through our website.

## Abstracts & Conferences

Our independent research provides real-world evidence which we present at medical conferences globally. This research covers all aspects of symptoms and diagnosis, treatment and disease management, and patient life quality and outlook. To date, the vast majority of our abstracts have been accepted and presented at conferences such as Lung Cancer Nursing UK Conference, ESMO TAT Congress, BTOG Conference, World Lung Cancer



Conference, and more. This global visibility gives ALK-positive lung cancer the spotlight it deserves to drive real change for patient outcomes.

## National Campaigns

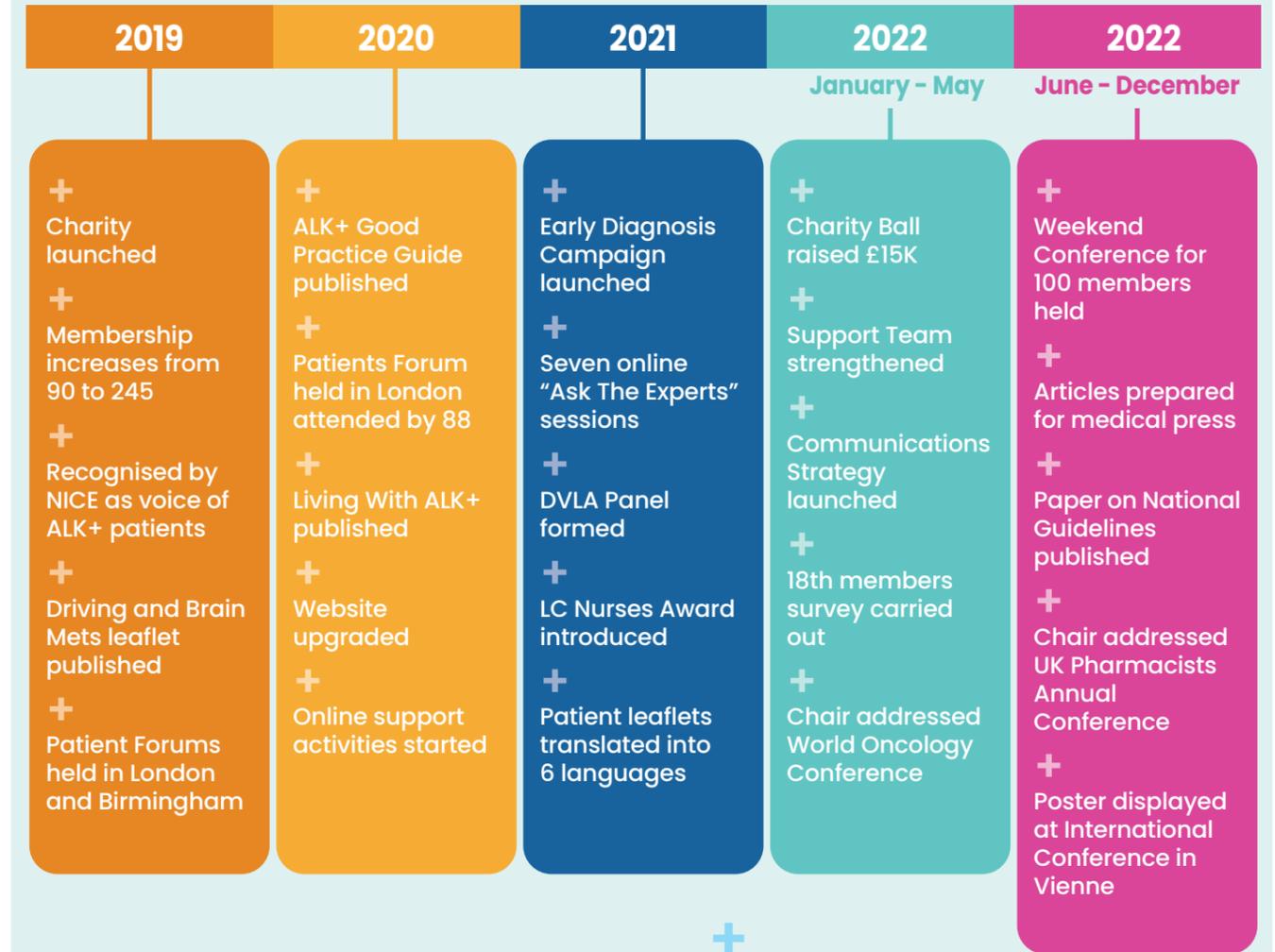
In 2021, ALK Positive Lung Cancer (UK) co-created, with EGFR+ UK and the Ruth Strauss Foundation, the national See Through The Symptoms campaign which emphasised the importance of early diagnosis to HCP audiences. The campaign gained national press coverage and had an incredible impact online. This campaign was the first of many targeted projects in the pipeline for ALK Positive Lung Cancer (UK) as part of our mission to improve patient outcomes across the UK.

## Patient Forums

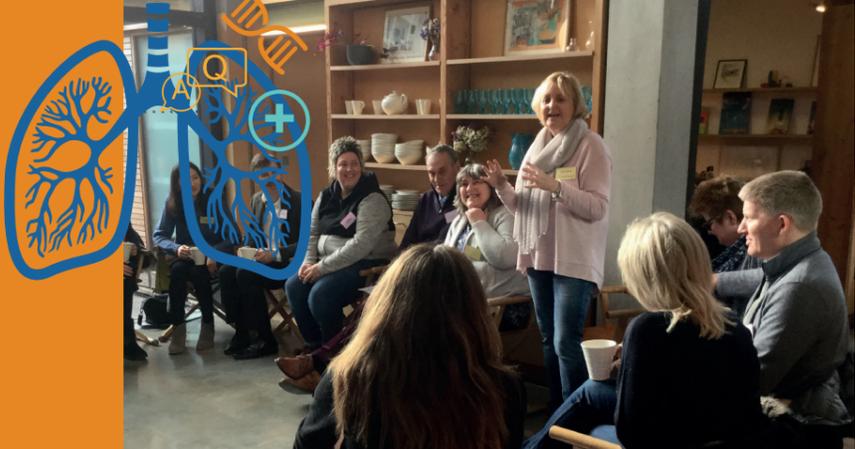
Part of our patient-driven activity involves our twice-yearly patient forums. These events encourage patients from across the UK to meet, share experiences and learn from medical professionals and experts in the field. These fully funded forums are hugely popular amongst the ALK Positive Lung Cancer (UK) community and empower patients to have a voice about their journey.



# Our timeline



# The ALK Positive Lung Cancer (UK) community



## Anyone with lungs can get ALK-positive lung cancer?

- + It has absolutely no correlation to smoking
- + It does not discriminate against gender, age or race
- + The only criteria is that you have a pair of lungs
- + Symptoms may include a persistent cough, breathlessness, chest/back pain and problems swallowing

84%



were diagnosed at stage 4

- + 4% of lung cancer patients are diagnosed with ALK Positive Lung Cancer. That's approximately 3,400 patients in the UK.

65%



are female

57%



were diagnosed at age 54 and under

77%



have never smoked

- + There are approximately 85,000 living with lung cancer in the UK.

## Valerie, one of our members, says:

“After 18 months of asking, I finally got a brain scan, thanks to the information I learnt on this site. My oncologist told me the last time that I spoke to her that she would be led by me as I know more about ALK+ than she does. This is all because of the work that has been done by this charity.”

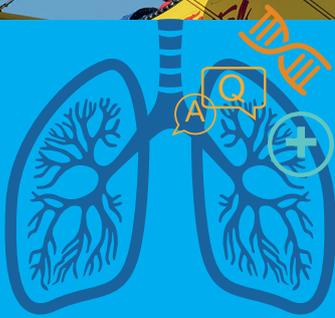
## Lynsey, a patient family member says:

“My husband's oncologist told him that she was on a Zoom conference with our Chair, Debra. She was very impressed and said that Debra's words had given her hope and had really impressed her.”

## National Institute for Health and Care Excellence (NICE):

“We found today's meeting to be really useful in exploring your already extremely helpful written submission in more depth and helped us unearth issues that were either new or not completely understood such as the real meaning and consequences of certain side-effects.”





“

Whilst **we have achieved** an incredible amount in the few short years we have been active, we need **more collaboration with healthcare professionals** and the **medical sector in general** to take our efforts to the next level. To implement real change for patients and overall survival outcomes, **we need the support and proactivity of nurses, doctors, GPs, surgeons, oncologists, pharmacists,** and every other HCP in between. Our ambitions are high, our attitude is tenacious, and our drive is unwavering - **be part of our journey to redefine the future for ALK-positive lung cancer** patients across the UK.

**Debra Montague,**

Founder and Chairwoman of ALK Positive Lung Cancer (UK)

**For more information** or to **collaborate with us**, please visit our website **[www.alkpositive.org.uk](http://www.alkpositive.org.uk)**, email us at **[hello@alkpositive.org.uk](mailto:hello@alkpositive.org.uk)** or call us on **07783 134437**. You can also write to us at **164 Guildford Road, Lightwater, Surrey, GU18 5RE.**

**Stay up to date** on ALK Positive Lung Cancer (UK)'s activities and accomplishments, as well as all other aspects of ALK-positive lung cancer by following us across our social media channels.



@UKALKPositive



@UKALK1



/ALKLungCancerUK



ALK Positive UK

