




2023

ALK positive UK

Our Impact



ALK Positive Lung Cancer (UK) registered charity (1181171)

Making a positive difference

2023 was the 4th full year since the Charity was formed by a small group of patients out of a desire to help fellow-patients and their families. With the support of our members, the charity has grown year on year to be the leading ALK-positive charity in the UK.

Our focus remains on improving the quality of life as people live longer with ALK-positive lung cancer. We do this by support, empowerment, advocacy and campaigning.

We are a small charity serving a relatively rare group of people and we do not have the public profile of the larger charities. We are heavily dependent on the fundraising efforts

of our members and we want to thank all those who did some amazing things in 2023.

But, this report is not about what we did in 2023 - that information is in our Annual Report, which can be found on our website and on the Charity Commission website. We think that it is well worth a read. This report is about the impact that we made in the year.

Debra

Debra Montague
Founder, ALK Positive UK



Satisfaction

The Charity commissioned an independent survey of its members and external stakeholders.

“

ALK+UK is an absolute pleasure to work with. You always provide a great voice of the patient community and work with us as industry in a true partnership manner. - Pharma partner

Read on

to find out how our vision to Support Empower and Advocate helps us achieve these world class scores

81%

of members were very satisfied with their membership of ALK+UK.

88%

of external stakeholders were very satisfied with their dealings with ALK+UK.

Our Net Promoter Scores were world class

83%

Members

100%

Clinicians

100%

Pharma

Support

The Support Group

We provide a private Facebook Support Group for 700 patients and their families to exchange experiences and to give and receive support.

98 

people joined the support group which represented a 14% increase in membership



On average, there are 115 posts per month attracting 1,220 comments and

3,430 reactions



Life Coach

We offered a Living With ALK+ Lung Cancer Coaching Service, providing 6-week online group sessions and also face-to-face coaching. Through self-management, individuals are empowered to regain control of their lives by understanding thoughts and emotions, strengthening mental resilience, identifying challenges, exploring different perspectives and setting goals.

22 

patients and partners of patients attended a session delivered by our Life Coach at our conference where the pressures on and needs of carers was explored.

“

The six-week session has helped me accept my cancer more than I could have expected.

“

The course gave me the chance to speak with others in similar situations and has helped me to realise that I am not alone. The course provided me with the opportunity to share ideas and concerns and lean on the support of others in a secure space.

22 

patients and 21 partners received support.

“

A great opportunity to talk to other carers.



Regional Meet-ups

We arrange regional lunchtime meet-ups for patients and families. These events are important to reduce feelings of isolation and promote mental wellbeing.

3 

meet-ups were held at 12 locations in the four nations comprising the UK.

81%

of those who attended the meet-ups found them to be valuable.



“

We have developed real, supportive friendships over the time we have been meeting.



Empowerment


The Website

Our website provides a source of accurate and reliable information for patients, families and healthcare professionals.

The website attracted almost

20,000

visits, an increase of

25% 

90% 

of new members said that the site provided the information they were looking for.

“

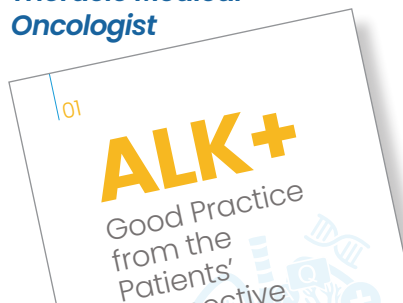
I like the wealth of information provided and how welcoming the website makes you feel.

The Good Practice Guide

The Charity has a guide for patients on the good practice that they should receive from their healthcare providers. The guide has been endorsed by leading lung cancer oncologists.

“

A great step forward. A good document that hits all the right spots. – Professor Sanjay Popat Consultant Thoracic Medical Oncologist



“

When one of our members was told by her consultant that she would have yearly MRI brain scans, she told him that ALK Positive UK recommend 6-monthly scans. The patient-focused consultant contacted us and we convinced him that 6-monthly scans are best practice. He is now introducing this protocol into his hospital.

Annual Conference

The weekend conference was attended by 140 patients and their families and heard from and questioned the UK's leading ALK-positive experts.

Attendance in 2023 was

40% 

higher than the previous year.

82% 

of delegates found the conference to be valuable.

The Do Not Resuscitate Leaflet

The Charity produced a leaflet advising patients and doctors how they should communicate about the possible placing of a DNR order.

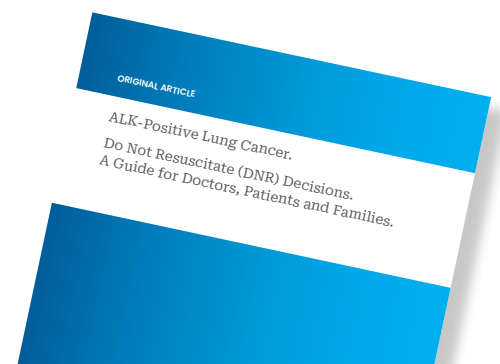
“

I successfully challenged a DNR using the information in this booklet.

Trusted Information

The Patient Information Forum aim is to advance health by setting high standards for health information for the public and patients to use.

We were awarded accreditation as a creator of trusted information.



Advocacy



Early Diagnosis Campaign

In collaboration with EGFR Positive UK and the Ruth Strauss Foundation, we launch a national campaign aimed at raising the understanding of primary care health professionals of lung cancer amongst non-smokers.

70%

of primary care providers who viewed the campaign said that they had learned something new.

52%

of these primary care providers said that they would use the new information in making referral decisions.



Social Media

We use social media to reach both a younger audience and healthcare professionals to raise awareness of non-smoking lung cancer and ALK-positive lung cancer; and to provide information about the Charity's services.

We reached over

1,000



followers on each of LinkedIn, Twitter and Instagram. We launched on TikTok in May.



My mum is newly diagnosed. We're trying to understand what we're dealing with and your resources are a lifeline.



We are trying to get information where we can and find your Instagram is such a great source of reliable facts.

"All You Need is Lungs" Campaign

In collaboration with EGFR Positive UK and the Ruth Strauss Foundation, we launched a national campaign using social media aimed at the general public to raise understanding that anyone with lungs can get lung cancer, including non-smokers.

We were blown away to learn that there were

60,000

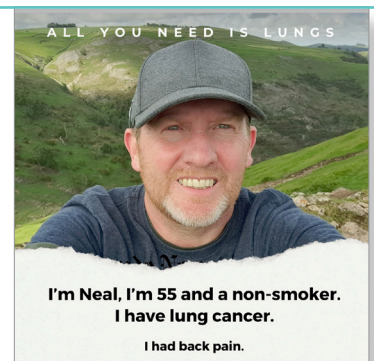
impressions across all platforms, indicating extensive reach.



Over

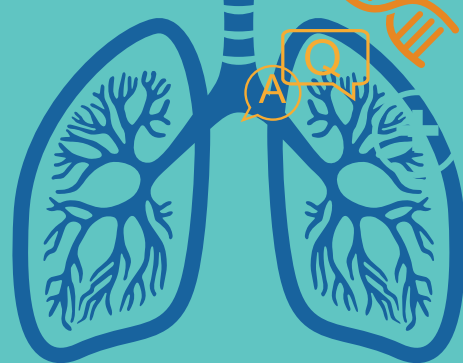
2,000

interactions indicating strong audience involvement.



Patients have typically never smoked and are often younger.

ALK Positive UK



ALK-positive lung cancer is a relatively rare form of lung cancer caused by the abnormal rearrangement of the anaplastic lymphoma kinase gene. The vast majority of patients are non-smokers, about half are under 50 years of age when diagnosed (some are much younger), and the majority are female. Most patients are diagnosed at Stage 4.

Our Mission

ALK Positive Lung Cancer (UK) exists to:

- + **Support** the ALK+ lung cancer patient community.
- + **Empower** people affected by ALK-positive lung cancer.
- + **Advocate** for improvements in the diagnosis, treatment and care of ALK-positive lung cancer across the UK.
- + **Represent** the voice of the ALK-positive lung cancer community.

Supports

We provide a forum where patients and their families can exchange information about their diagnosis and treatment, and where they can give and receive mutual support.

Empowers

We are a source of information for patients so that they are better informed about their condition and, as informed patients, they are empowered to ensure that their health care providers employ best practice.

Advocates

We advocate on behalf of patients to ensure that they receive a high level of care wherever they live in the UK and to promote improved patient outcomes. We campaign for early diagnosis so that more patients can be cured.

Join our growing community and help us drive ALK change



Find us at: www.alkpositive.org.uk



ALK Positive Lung Cancer (UK)

Old Carw Farmhouse, Carrow Hill, St Brides
Netherwent, Caldicot, Monmouthshire, NP26 3AU
hello@alkpositive.org.uk T: 07783 134437

Chair: Debra Montague
Finance: Andy McKay
Secretary: Graham Lavender

ALK Positive Lung Cancer (UK) is a registered charity in England and Wales, registration number 1181171