ALK Positive Lung Cancer (UK)

5th Annual Patient Conference

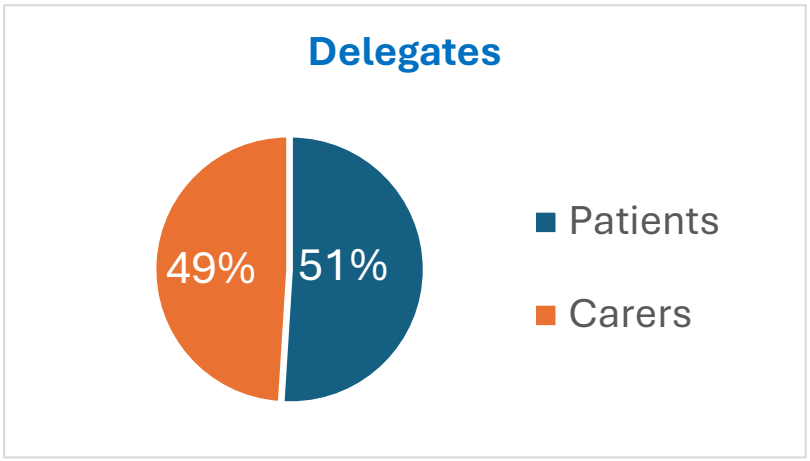
September 2026



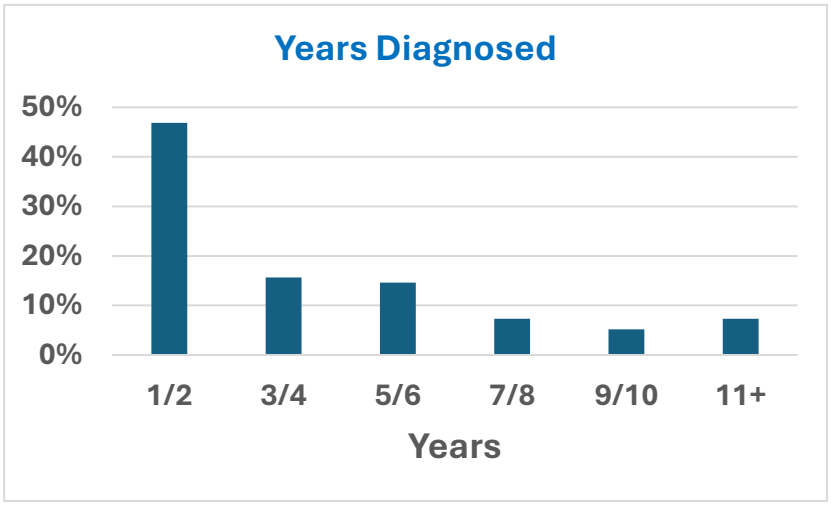
ALK Positive UK's 5th national weekend conference for patients and carers was held in September 2026 at the Radisson Red Hotel, London.

Attendance at the conferences has increased from 100 in 2022, 140 in 2023, 148 in 2024, 190 in 2025 to 215 in 2026. This is the largest gathering of people affected by ALK-positive lung cancer in the world, outside the USA.

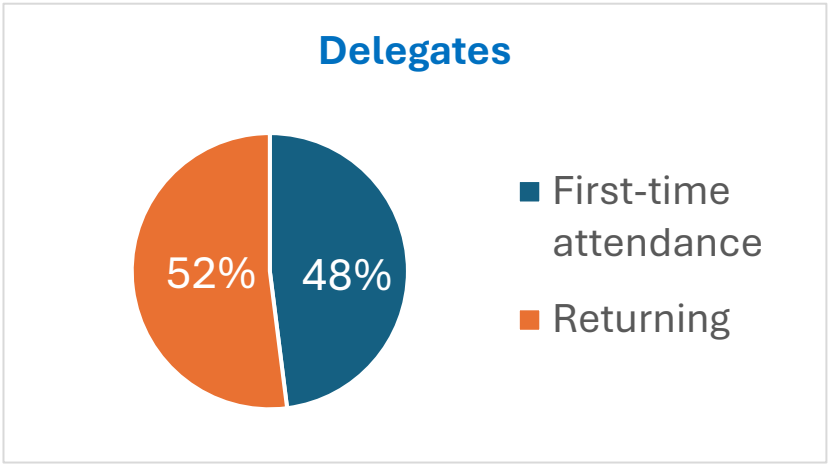
Of the 215 delegates, about half were patients and half were carers.



Nearly half the delegates had been diagnosed less than 2 years, The wide range indicates that the conference is valued by patients at all stages of their cancer journey.



Just over half of delegates had attended a previous conference. The high number of returns indicates the value delegates gained from attending previous conferences

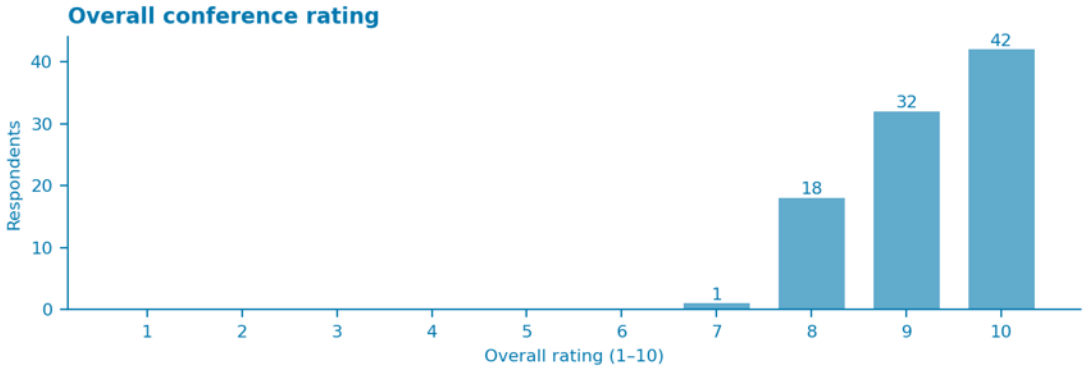


Feedback

Following the conference, delegates were asked to complete anonymously an online feedback survey. The response was overwhelmingly positive.

The Net Promoter Score is a recognised measure of the success of a conference and a score of over 30 is considered excellent. This conference achieved an amazing

Net Promoter Score = 93



Statement	Agree or strongly agree
I have a better understanding of ALK-positive lung cancer	99%
I have a better understanding of where to find trusted information and support	96%
I feel more connected to other people affected by ALK-positive lung cancer	96%
I feel more confident having meaningful conversations with my healthcare team	92%

What some of the delegates said.

"It was a fantastic event and we thoroughly enjoyed ourselves, learned masses of stuff and have made some wonderful new friends."

"Thank you so much for organising this event. I am so very grateful to everyone else who made it possible. I know I would be very lost had I not found this amazing charity and I really appreciate all your hard work."

"Thank you, this was my first conference, came with no expectations but left with more knowledge and friendships than I expected."

"Exceedingly well organised conference with very knowledgeable medical professionals sharing their knowledge and experiences."

"Thank You for making myself and the other sufferers feel important and supported in our individual journeys."

"Thank you for arranging a fantastic conference. Without this I may never have met other ALK patients and made so many new friends. Thank you so much ."

Speakers



Debra Montague, Chair of the Charity, welcomed guests, many of whom were veterans of our conferences but also many here for the first time. Debra had a special word for those who had been recently diagnosed and said that they were amongst friends who completely understood what they were feeling.

“Over the weekend, we are going to hear from some outstanding clinicians and experts. We are enormously fortunate that they give their time so generously to come here, share their knowledge and – importantly – answer our questions.

“And I want to give a particularly warm welcome and thank you to our keynote speaker, Dr Tom Newsom-Davis, who has been a great supporter of the charity.

“Thank you to our trustees, our volunteers, our speakers and everyone who has worked incredibly hard behind the scenes to make our fifth conference happen.

“And most of all, thank you for being here and for being part of this rather remarkable ALK-positive family”.



Keynote Speech

Dr Tom Newsom-Davis, Consultant Oncologist, Chelsea & Westminster Hospital, Chair of British Thoracic Oncology Group Steering Committee.

Medical advancements over the past two decades have dramatically improved outcomes for lung cancer patients, transforming a historically bleak diagnosis into a condition with significant reasons for hope.

Dr Newsom-Davis highlighted that while older diagnostic approaches and therapies were severely limited, modern treatments allow for rapid molecular testing and targeted interventions that successfully manage symptoms and extend survival.

Despite these innovations, younger lung cancer patients face unique challenges, including delayed diagnoses due to a lack of routine screening and the common misconception that the disease exclusively affects older smokers. Furthermore, young patients—who are disproportionately female and non-smoking—frequently encounter heightened psychosocial burdens, such as severe isolation, guilt, stigma, and difficulties balancing family caregiver responsibilities.

Healthcare systems must adapt by ensuring comprehensive molecular profiling, improving clinical communication regarding sensitive topics like fertility, and providing better mental health support. Ultimately, addressing these disparities requires clinicians to think beyond standard paradigms, offering tailored treatments and clinical trials to better serve this vulnerable population.



Clinical Trials

Dr David Gilligan, consultant clinical oncologist at Cambridge University Hospitals and Royal Papworth Hospital and associate lecturer at the University of Cambridge.

This session aimed to empower patients and caregivers by providing an overview of current treatment standards, future therapeutic pipelines, and the resources available for navigating clinical trials.

Dr Gilligan spoke about the advancements and ongoing investigations in clinical trials for ALK-positive lung cancer. He examined landmark research, such as the Crown and Alina studies, which highlight the remarkable effectiveness of advanced targeted therapies in staving off disease progression and preventing tumour recurrence.

He discussed the exploration of local consolidative therapies and the strategic application of radiotherapy for patients whose cancer has spread to a limited number of sites. He detailed the rigorous criteria and practical realities of accessing emerging experimental drugs, alongside the immense value of non-interventional research initiatives like the Enlightened study in mapping environmental and genetic risk factors.



Cancer Signalling Pathways

Professor Richard Bayliss, School of Molecular & Cellular Biology, Leeds University.

This session was about why specific mutations, such as the EML4-ALK fusion, drive uncontrolled cell growth in non-small cell lung cancer. Professor Bayliss detailed how protein kinases operate molecular switches within cells, highlighting that ALK inhibitors effectively halt this process by blocking ATP binding at the molecular level.

While these targeted drugs succeed initially, resistance frequently develops through on-target mutations or off-target mechanisms where alternative receptors take over. To combat these challenges, researchers now utilise artificial intelligence like AlphaFold to dramatically accelerate the design of entirely new proteins and therapies.

Closing the gap between laboratory discoveries and clinical trials requires closer collaboration between scientists and patients to develop faster treatments.



Survivorship

Dr Natalie Doyle, former Nurse Consultant, Living With and Beyond Cancer, The Royal Marsden Hospital, London.

Dr Doyle emphasised that cancer survivorship extends far beyond clinical treatment, highlighting the critical need to view patients as holistic individuals rather than merely a diagnosis.

She discussed how living with chronic illness introduces profound uncertainty and alters one's perception of time, identity, and daily existence. To navigate this emotional and psychological roller coaster, patients must be empowered to prioritise what truly matters to them in their personal lives.

She advocates for shared decision-making between healthcare professionals and patients, ensuring that medical care adapts to the individual's needs rather than dictating them.

Fostering supportive networks and asking "what matters to you" helps restore a vital sense of control and meaning.



Patient Voices

Joanna Vick, Lead Lung Clinical Nurse Specialist, The Royal Marsden Hospital, London.

Jo chaired a panel of patients who shared their personal journeys and coping strategies during a discussion on managing the emotional and physical challenges of a lung cancer diagnosis.

The panel highlighted the initial shock and fear of confronting their own mortality, while also addressing the complex process of sharing the news with young children and loved ones.

Participants emphasised the importance of patient advocacy, effective communication with medical teams, and engaging with support networks to regain a sense of control. Additionally, the conversation explored the chronic anxiety surrounding medical scans and the ways individuals strive to maintain a normal, active life despite ongoing treatments.

The charity wishes to record its thanks to four brave patients, Becky Davis, Lisa Becket, Traceydawn White and Shaun Hill, who shared their emotional challenges with the audience.



Management of Lorlatinib

Professor Alastair Greystoke, Professor of Oncology, Newcastle University.

Professor Greystoke provided a comprehensive medical overview of lorlatinib, a third-generation targeted therapy used to treat ALK-positive lung cancer both as a second-line option and a frontline treatment.

The presentation highlighted the drug's exceptional central nervous system penetration and its ability to effectively shrink tumours and manage brain metastases, even after previous treatments.

He discussed significant side effects such as high cholesterol, weight gain, peripheral neuropathy, and mood changes, emphasising the importance of proactive management and tailored dose reductions to maintain patient quality of life.

He explored the complexities of tumour rebiopsies, liquid biopsies, and ongoing uncertainties surrounding resistance mechanisms and long-term treatment strategies.



Advice from the Pharmacy

Ms Rachel Patel, Cancer Pharmacist.

Rachel Patel discussed safely managing ALK inhibitors alongside everyday substances and medical treatments. She emphasised that cancer patients must never guess about potential drug interactions involving new prescriptions, over-the-counter remedies, vaccines, or herbal supplements.

She suggested practical strategies like verifying exact medication names, avoiding double doses when schedules are missed, and thoroughly checking product ingredients before consumption.

She addressed specific clinical concerns such as contraception safety, weight-loss medications, and appropriate storage techniques to prevent tablet degradation. She urged patients to proactively stop, show, check, and share all health products with their oncology team to prevent avoidable risks.



Open Q&A

Dr Shobhit Baijal, Consultant Oncologist, University Hospital, Birmingham.

Dr Baijal returned for a 5th year to respond to a wide range of questions in an open Q & A session.

The discussion covered practical topics such as managing treatment side effects, navigating logistical challenges like scheduling scans, and assessing the safety of lifestyle changes and short medication breaks.

Dr Baijal also explained the complexities of treatment resistance mechanisms, the limitations and high costs of liquid biopsies, and the importance of personalised brain surveillance.

He provided insight into emerging therapeutic landscapes, including next-generation TKIs, vaccines, and chemotherapy options, while emphasising the necessity of maintaining open communication with healthcare teams.



Update on her Research

Roxane Chen. PhD student, Cambridge University.

Roxane presented an update on her scientific work regarding ALK-positive lung cancer, focusing on identifying bypass resistance mechanisms and understanding treatment side effects.

Her experimental approach utilizes CRISPR activation screens and lab-grown cell lines to determine why specific cancer cells survive tyrosine kinase inhibitor therapies. To ensure clinical relevance, she compares her laboratory findings against patient biosamples gathered through ongoing feasibility studies.

Additionally, she investigates medication-induced toxicity like fatigue and muscle weakness using animal models to evaluate chronic treatment impacts. This research highlights the gradual progression of scientific discovery and the collaborative efforts required to improve outcomes for affected patients.



Update from the Charity

Debra Montague, Chair

Debra outlined the comprehensive support and empowerment of patients that the charity provides, including the national conferences, regional lunches, life coaching and a wide range of publications. The charity also advocates nationally for best practice throughout the UK and campaigns for early diagnosis.

The organisation relies heavily on patient surveys and data collection to influence clinical standards, secure pharmaceutical funding, and produce informative reports that highlight the real-world challenges patients face.

The charity's activities are founded on good governance and sound finance. We embrace modern tools like artificial intelligence to maximise operational efficiency and cost-effectiveness.

In addition to offering a hardship fund for members in financial distress, the charity maintains a strong presence across various social media platforms to raise public awareness and connect with the healthcare community. The organisation depends on the active engagement and financial contributions of its growing membership to sustain and expand its vital services for patients and their families.
