ALK Positive Lung Cancer (UK)

2025 Conference Report

ALK Positive UK's 4th national weekend conference for patients and a family member was held in September at the Radisson Red Hotel, London.

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

The conference commenced with a dinner on Friday evening.

The Chair of the Charity, **Debra Montague**, 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.

Her message to delegates was –

- Ask questions – our medical experts are here for us
- Share stories – your experiences are invaluable to others
- Make connections – exchange numbers with those who may live near you
- Hold on to hope – science is moving at a breath-taking pace.

Debra introduced the keynote speaker, **Professor Sanjay Popat**, Consultant Medical Oncologist at The Royal Marsden Hospital and also the Charity's Honorary Clinical Advisor.

Professor Popat spoke about the amazingly rapid developments that had taken place in recent years. It wasn't long ago that ALK-positive lung cancer was discovered and now a range of treatments is available. We have gone from 1st generation drugs to 4th generation in a very short time. He said that we are living in amazing times. He said that two new classes of drugs show great promise – antibody drug coagulates and molecular glues – and there are more in the pipeline.

Whilst screening of high risk smokers is effective, identifying lung cancer at an early stage in non-smokers is proving to be difficult. He spoke about quality of life and that adding more drugs create more side effects. A balance needs to be found.

Professor Popat ended by proposing a toast to ALK Positive UK and all that it had achieved.

Dr Sharmistha Ghosh was the first speaker on Saturday morning. She is a Consultant Medical Oncologist at Guy's and St Thomas' Hospital, London. Last year, she interrupted her ward round to speak to the conference virtually but was welcomed in person this year.

Dr Ghosh explained why cancer patients are more likely to experience blood clots (venous thromboembolism – VTE) with 20% of all VTEs occurring in cancer patients. In a trial, almost half of the ALK-positive patients experienced blood clots, nearly double the rate of other lung cancer patients.

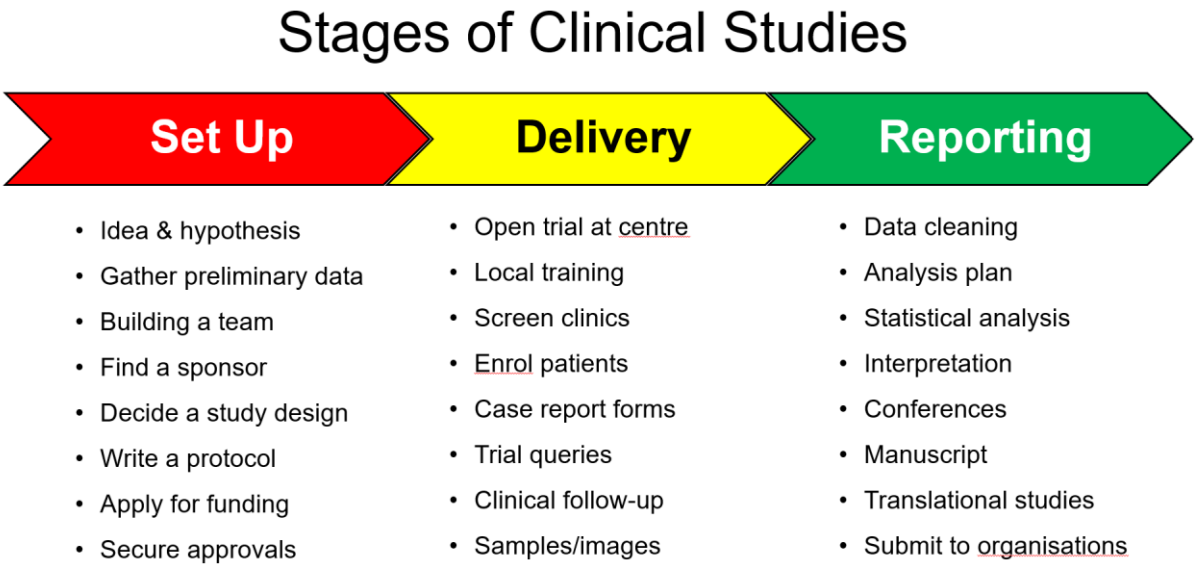
She said that small clots may be found on scans but most clots will be diagnosed when symptoms arise. Clots can arise anywhere but often in the leg showing a red, hot, swollen or tender area. When clots are in the lung, they often cause breathlessness.

First line treatment is now usually a direct oral anticoagulant (DORC) taken once or twice a day. Patients may be prescribed treatment for several months if the clot was small or for years if the clot was large. When taken long-term, it acts as a prophylactic preventing new clots. It is considered that the benefits outweigh the risks of bleeding.

In reply to questions, Dr Ghosh said that patients should keep hydrated and mobile at all times, especially on flights, when stocking should be worn.

Dr Gerard Walls is a Clinical Senior Lecturer and Honorary Consultant in Clinical Oncology at the Northern Ireland Cancer Centre and an Academic Clinical Lecturer at the Patrick Johnston Centre for Cancer Research, Belfast.

Dr Walls talked about busting the jargon of clinical trials. He explained the development process, taking many years from an idea or hypothesis before the first person of perhaps 10 would be enrolled in phase I of a trial. There would then be many more years of further phases, assessment of results, publication of results, evaluation and regulatory consideration before a drug became available to the public.



Dr Walls explained the layout of published reports on trials. He suggested that patients should start with the Abstract at the beginning of a report, as this gave a short summary of the purpose of the trial, methods, used, results and conclusions. They should then look at the Discussion at the end of the report before attempting the complex information in the body of the report. He recommended the use of Artificial Intelligence to produce a short summary of reports.

Dr Walls answered questions on randomisation, crossover in trials and about the absence of a unified directory of world-wide trials.

Dr Inigo Perez-Celorrio, DVLA Doctor, gave an insight into fitness to drive with particular reference to brain metastases. He outlined the law and explained the role of the DVLA Medical Panel.

He said that drivers had a legal duty to report any medical condition that seriously affected their ability to drive. He advised drivers to surrender their licences and not wait for them to be revoked.

Is a brain met is found and the driver is not showing any symptoms and the oncologists decides to observe the brain met and not to treat it, the driver does not need to surrender the licence. But, if the oncologist decides to treat the met, including a change of TKI, the licence has to be surrendered.

He emphasised the importance of understanding Section 88 of the Road Traffic Act which applies if a licence is surrendered but not if the licence is revoked. If a driver has surrendered their licence and the brain met is stable or diminishing, they can apply for a licence two months in advance of the 12-month surrender period. Section 88 allows them to drive whilst the DVLA is considering their application.

In reply to a question, Dr Perez-Celorrio said that insurance companies might not know about Section 88.

[patients should not rely on anything in this note as being a statement of fact concerning the law or fitness to drive]

The Debate

At previous conferences, Professor Greystoke and Dr Newsom-Davis conducted lively debates about

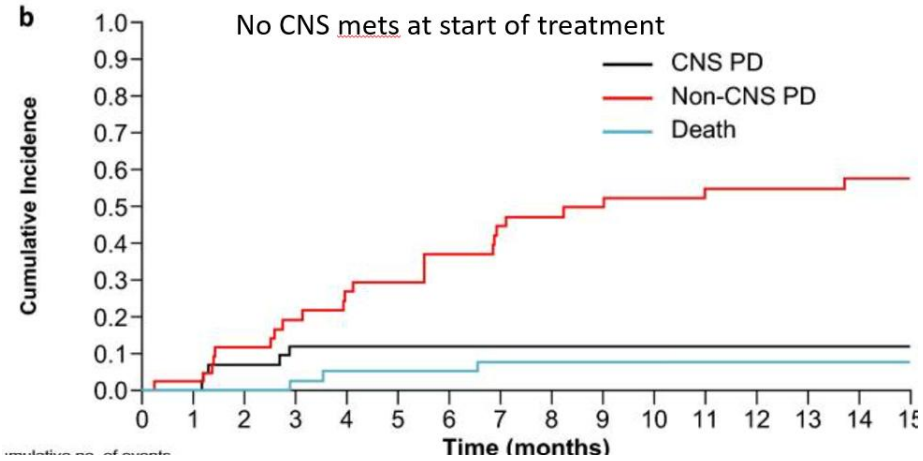
(a) Should Lorlatinib be used for 1sr line treatment
(b) Should patients be treated at local hospitals or at major cancer centres

This year they debated whether patients should receive regular brain imaging in the absence of symptoms. The positions taken by the two oncologists were for the purpose of debate and did not necessarily reflect their views.

Professor Greystoke made the case for regular brain MRIs in the absence of symptoms and Dr Newsom-Davis the case against.

Professor Alastair Greystoke, Medical Oncologist, Northern Centre for Cancer Care, Newcastle. Professor Greystoke's principal argument was that it was better to find brain metastases while they were small and few in number. Tumour volume can increase at a rate of nearly 2% a day and double in 2 months.

He said that, if brain mets are found early, there is a better chance of them being able to be radiated and avoid the need for the patient to switch to a new TKI.



He said that the more area that has to be radiated, the higher the risk of radionecrosis.

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

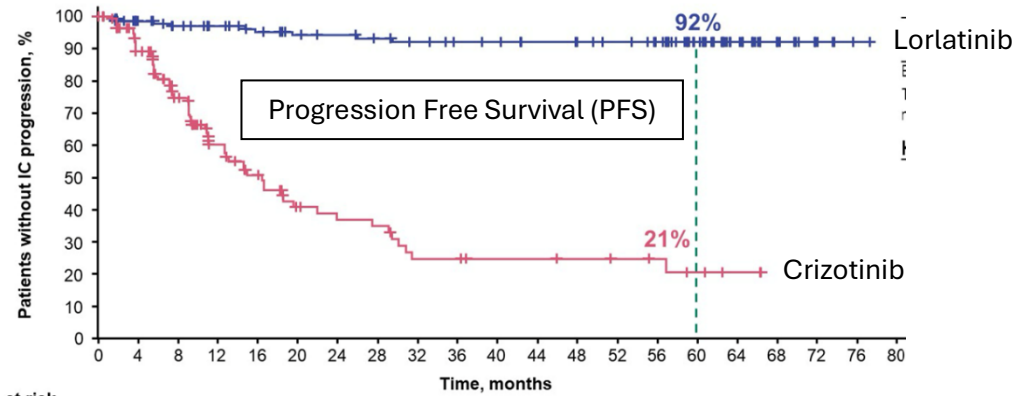
Dr Newsom-Davis said that regular brain scans can only be justified if they

- helped patients to live longer, or
- help patients to live better lives

He said that there is no evidence to justify routine brain scans.

Also, there is no UK guidance about regular brain scans and European and American guidance did not include routine brain scans.

He said that the latest TKI are very good at preventing brain mets and mentioned the results of the Lorlatinib trial which showed that, after nearly 7 years, 92% of patients in the trial did not have brain mets.



He also said that many patients suffer claustrophobia at the thought of the MRI scanner and that scanxiety is real for many patients whilst they await the results of scans.

Dr Newsom-Davis concluded by saying that, just because we can do something, shouldn't determine what we actually do.

In response to questions Professor Greystoke acknowledged the effectiveness of the current TKIs in crossing the blood-brain barrier.

Dr Newsom-Davis acknowledged that the lack of evidence about the effectiveness of regular brain scans was due to a lack of relevant studies.

Other matters discussed included

- availability of MRI scanners
- shortage of radiologists
- post code lottery was not an issue
- local protocols

The Vote – by a large majority, delegates voted for 6-monthly brain MRI scans when there were no symptoms.

Roxane Chen, iBSc (Hons), PhD student at Cambridge University.

Roxane address a packed hall at an early morning session on Sunday morning.

She said that her PhD thesis would be about

- Better understanding ALK TKI side effects and possible management strategies, and
- Identification of bypass resistance pathways and combination treatments for clinical trial validation

She illustrated how the ALK mutation causes cancer and the challenges which researchers have to overcome. In particular, why each TKI produces its own side effects and how bypass resistance comes about.

Roxane explained the difference between “on-target” and “off-target” resistance.

She said that there is still a lot to learn about the role of ALK in the body and pure research is needed.

She elaborated on her collaboration with Professor Popat at The Marsden, Dr Gomes at The Christies and The National Oncology Trainee Collaborative for Healthcare Research (NOTCH).

Roxane concluded by saying that the take home message is HOPE and that research is progressing rapidly.

Debra thanked her for her dedication in trying to learn more about ALK-positive lung cancer and hoped that she would keep us informed of her progress.

Dr Clive Peedelli is a Consultant Clinical Oncologist at James Cook University Hospital, Middlesborough with a special interest in radiotherapy. He addressed conference on what’s new in radiology. He gave a brief history of the development of radiotherapy and the technical advances leading to today’s MRI guided adaptive radiotherapy and “dose painting”.

He said that the “holy grail” of radiotherapy was to deliver a curative radiation dose to the tumour without causing significant damage to normal tissue. He elaborated on stereotactic ablative radiotherapy (SABR) which delivers precise irradiation of an image-defined lesion with the use of a high radiation dose in a small number of fractions.

He said that about half of cancer patients will require radiotherapy at some point, either in a curative, adjuvant or palliative setting. Surgery remains the gold standard for early stage patients but cannot be carried out on all patients and then SABR is offered with a high level of success.

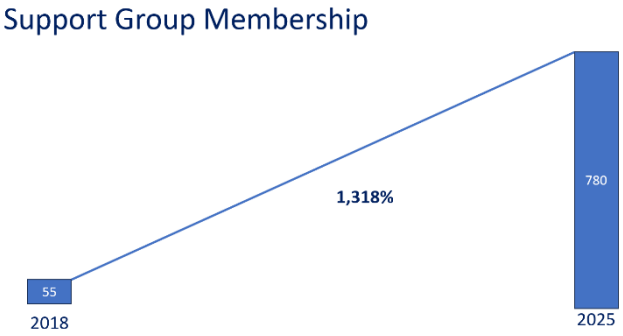
Dr Peedell said that dealing with oligometastatic progression was now a standard practice, especially for Stage 4 patients taking targeted therapies. It was usual to radiate up to 5 lesions, although tumour volume is an important consideration. This could give patients extra time on their TKI, sometimes for many years. The results of the HALT trial are expected shortly and should answer questions about the benefits of oligometastatic radiation.

Outcomes from SABR and whole brain radiation (WBR) were similar but WBR came with significant side effects and should be avoided if possible.

Dr Peedell concluded by saying that his approach was if there is limited disease go after it.

Debra presented an update of the charity in two parts – what has been achieved in the past year and what is planned for the next year.

The website has been given a refresh and now focuses more on providing support to newly diagnosed patients. We have improved the pathways for finding information and continue to add to the site.



The online support group continues to grow and Debra thanked members for their contributions to the exchange of experiences and to answering the questions that other members ask.

Our recent publications include Frequency of Head MRIs; Do Not Resuscitate Orders; Financial Hardship; Brain Tumours and Driving.

We have been increasing our presence in the regions and Andy McKay (Scotland), Stuart Griffith (Wales) and Irene Crozier (NI) are now representing the charity.

The regional lunches continue to be an important opportunity for members to meet and we are very grateful to our Regional Ambassadors for arranging these.

We are told that younger people are often not users of Facebook and we are expanding our presence on all the various social media platforms.

Looking forward, Debra said that she is delighted to announce the launch of the Brenda Cobb Hardship Fund.

BRENDA COBB HARDSHIP FUND

Our survey of members showed that 1 in 4 is experiencing significant hardship as a result of their diagnosis and the hardship fund is available to them. We haven't limited the use to which the fund can be used, except that it must be for the benefit of the patient and/or their family. We are very grateful to Brenda's son, Callum, for providing the money for the fund from his amazing world-wide fundraising marathons.

Emma Britton is a newly diagnosed patient and is also a radio presenter. Over the next year, she is going to conduct a series of interviews with some of our members to ask them about their experiences.

During the pandemic, we organised several "Ask the Expert" online meetings and these are on the website. We now plan to hold another three on Alectinib, Brigatinib and Lorlatinib.

We are discussing with our Life Coach, Jane Woods, the possibility of arranging one or more Weekend Retreats and several members have expressed interest. Early days but we will keep members informed.

Every few years, we ask patients to complete a questionnaire about ALL aspects of their diagnosis, treatment and care. Data provided by patients enable us to advocate for best practice throughout the UK and Ireland. We will shortly be asking ALL patients to complete a new questionnaire.

We are delighted to announce that Lynsey Conway has been appointed as our CEO. Lynsey is the External Affairs Lead, UK Lung Cancer Coalition (UKLCC) and has worked for over 25 years in the lung cancer arena. She brings a wealth of experience that will be invaluable to the charity. Her appointment is a major step in ensuring the long-term sustainability of the charity.

Dr Shobhit Baijal, Consultant Medical Oncologist at University Hospital, Birmingham, led an open Question and Answer session. We had asked members who were unable to attend to let us have questions that they would like to ask but it was not possible to include all of these. Dr Baijal answered a wide range of questions on various topics, including

Severe fatigue on minimal dose of Alectinib	Early diagnosis
Switching to Lorlatinib before progression on Alectinib	Skipping Lorlatinib and going from Alectinib to the Nuvalent drug
Chemotherapy before TKI	When to biopsy
Chemotherapy after TKI	Tissue banks
Bone strengthening medication	Lorlatinib 1st line
Liquid biopsies before progression	Rethinking staging

It isn't possible in this report to include his responses but the video of this session is well worth viewing.

It is not possible to capture the depth and breadth of all the matters discussed at the conference but videos of all presentations, discussions and what the delegates thought can be viewed at

UK Conference Sept 2025 | ALK Positive UK

The Charity is pleased to acknowledge the financial contributions towards the cost of the conference made by Callum Cobb, Blackwell Foundation, Takeda, Pfizer, Nuvalent, Roche Products Limited and Thermof Fisher Scientific who had no control over the content of the meeting

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

> *Wonderfully organised and executed with fantastic speakers and great opportunities to socialise with other patients.*
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> *What has been organised and how it is done, is beyond belief!! The quality of the input is exceptional.*
>
> *The conference was very interesting and informative and I now know much more about my sister's lung cancer and how I can support her.*

We also asked delegates for suggestions as to how we can improve future conferences and we will take into consideration all the constructive comments received.

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