



## ALK Positive Lung Cancer UK - 2023 Conference Report

The Charity held its second annual conference for patients and caregivers over the weekend of 22-24 September 2023 at the Radisson Red Hotel, London Heathrow. The conference had a record attendance of over 140, including many newly diagnosed patients looking to learn more about their condition and to find some reassurance and hope.



The conference started on Friday afternoon with a “coffee and cake” networking session, allowing attendees to introduce themselves, to get reacquainted with old friends and to meet new ones. This was followed in the evening by dinner and a keynote speech by Professor Sanjay Popat, Medical Oncologist, The Royal Marsden Hospital, and Honorary Advisor to ALK Positive UK. Professor Popat delivered a message of hope on how far treatment of ALK Positive Lung Cancer has come in just 10 years and how much new and innovative work is ongoing right now.

The conference started proper on Saturday morning with a session from Dr Fabio Gomes, Medical Oncologist, The Christie, who outlined the ALK Education project which aims to bring a better understanding of ALK+ NSCLC to healthcare professionals in both secondary and primary care, as well as patients and caregivers. Dr Gomes then led an interactive session to gather patient and caregiver points of view to inform his project.



The following session was by Ms Francesca Tabacchi, Oncology Dietician, Oxford University Hospital, on the subject of diet and nutrition. Many of the myths about what to eat as a cancer patient were explored, and we learned that “just a Babybel cheese and a handful of nuts contains enough fat to aid absorption of a TKI dose” (the charity is not sponsored by or endorse Babybel!)

Whilst patients were receiving dietary advice, there was a separate, relaxed and participative session just for partners/carers to share experiences. The session was facilitated by Jane Woods, our Life Coach, who suggested coping mechanisms for dealing with stressful situations.



In the afternoon, conference restarted with the debate between Professor Alastair Greystoke, Medical Oncologist, Nother Centre for Cancer Care and Dr Tom Newsom-Davis, Medical Oncologist, Chelsea & Westminster Hospital. The topic of this year's debate was the pros and cons of local vs. regional care for ALK+ patients. After last year's heavy defeat, Professor Greystoke was determined to make a strong case for local care and treatment, but Dr Newsom-Davis forcefully put the case for regional centres of care. An

interesting and informative debate ended with a show of hands from the attendees – pretty much a dead heat, meaning we will no doubt need another rematch next year! It should be noted that the positions taken by the two consultants was for the purpose of debate and did not necessarily represent their personal views.

We rounded off Saturday with a talk by Dr Anna Minchom, Medical Oncologist, The Royal Marsden and Clinical Scientist, Institute of Cancer Research. Dr Minchom outlined the state of clinical trials in the UK, including the Nuvalent trial, how they operate and how to work with your medical team to find one that is right for you.

On Sunday morning, our Chair and Founder, Debra Montague, gave an update on the charity and what we have been doing in the past year, detailing all the fundraising, support and advocacy work which are the core of what we do.



There then followed a session from Ms Sinead Garry, a welfare rights advisor from Macmillan Cancer Support, on the various benefits available to cancer patients. If there was one message we all took away from this session, it was “don't apply on your own – reach out for help from the experts.”

The next session delivered by Ms Faye Dickinson, Physiotherapist, Guy's & St Thomas Hospital, was on the importance of prehab – that is using diet and exercise to prepare us for treatment and the difference it can make to outcomes post-treatment. A simple message – the healthier you are going into treatment, the healthier you will be coming out of treatment!



We closed out the conference with a session led by Dr Shobhit Bajjal, Medical Oncologist, University Hospital Birmingham. Dr Bajjal very bravely agreed to stand up with no pre-defined topics and just answer patient and caregiver questions. We kept him talking and answering a wide range of questions on the benefits of different TKIs, dosage decisions, second opinions and even his view on future treatment options. We're sure many attendees came away deciding to spend some time reading up on Antibody Drug Conjugants.

And with that we were all done. Another informative, inspiring and uplifting national conference in the bag. We hope that we achieved a good balance between the formal sessions and opportunities for delegates to exchange experiences with and to learn from other delegates. We look forward to seeing you all again next year plus many more.

We asked delegates for their feedback and the vast majority scored all the speakers highly for their delivery and content. We also asked about the administration of the conference and the venue and again received very positive feedback together with constructive suggestions. Some of the unsolicited comments were –

“This conference was powerful for me, personally, both in terms of meeting others with ALK+ LC but also compelling me to get involved in the Education Project and in other ways. Thank you so much for a great conference!!!”

“Great conference. The weekend was so well organised and I really appreciate all the effort put on keep doing what you do.”

“Really enjoyed the conference, great to meet others, good to have plenty of time to meet others.”

“The conference was outstanding - a warm, inclusive atmosphere, informative sessions with experts in their fields.”

“It was great. It was lovely to meet other people going through the same thing. To be given all that advice and to be so well looked after while we were there.”

We will take all the feedback into account when we plan next year’s conference.



Debra Montague  
Chair

Duncan Edmonstone  
Chief Executive