



Inaugural Meeting of ALK POSITIVE UK Group

Hilton Hotel Terminal4 Heathrow Saturday 7th July 2018

Present

Patients

Amanda Sands
Carolyn Crayon Radar Robbins
Debbie Gardener
Debra Montague
Doreen McGinley
Maureen Sawyer
Merete Baksh
Sally Hayton

Carers

Debbie's partner
Denise
Deshani Monik
Frank Talton
Graham Lavender
Rachel Sands
Rebecca Stebbings

The meeting was chaired by Debra Montague.

Debra welcomed those present and thanked them for making the effort to attend. She also thanked Deshani for arranging the use of the Hilton Hotel at a preferential cost.

Each ALK+ patient introduced themselves and spoke a little about their lung cancer (LC) history and their current status. As the meeting coincided with the football World Cup, each person present signed a football.

Debra welcomed Dr Sanjay Popat, a UK ALK+ expert and consultant at the Royal Marsden Hospital. Dr Popat said that he was delighted that the group had been set up and hoped that it would become an influencer at a national level. His presentation covered

Explanation of the classification of LC

Development of the understanding of gene mutation

Discovery of the ALK gene
Development of TKIs (1st, 2nd and 3rd generations)
Approvals (USA, Europe, UK)

He identified the current issues as -

TKIs v chemo
Control of brain mets – access to SRS (few hospitals with technical expertise)
Access to drugs (who pays – comparison made between USA and UK)
How to cure, not just control

Dr Popat then dealt with a range of questions covering –

Benefits of bone-strengthening injections
Biopsies
Process of clinical trials
Distinction between medical ONCs (drug & trials orientated) and clinical ONCs (drug & radiation orientated) and the need for ALK patients to be treated by medical ONCs
Shortage of ALK specialists
Limited use of immunotherapy after ALK inhibitors (but more work is being undertaken)
DVLA guidelines re brain mets
Private biopsy options – Dr Popat recommended Gardiant 360 £4k although findings may not be in line with NHS approved treatments
Dr Popat's closing remarks 'blokes like me don't make change/progress happen, it's people like you...'

The 30 minutes allocated to Dr Popat stretched to 1 hour 15 minutes.

Dr Popat was thanked for his informative contribution.

Martina McGill from Macmillan Cancer Information Support Service then spoke of the services offered by her organisation, including –

Help line
Face to face support
Mobile units
Fund raising
Macmillan pharmacists
Website
Start-up grants
PIPs

There was then a general discussion about the future of the group, including –

Purpose(s) of the Group
Frequency of meetings (at this point a shout went up as Rachel reported that England had scored a goal)
Structure

Charitable status

Communications - Face Book/Whats App/Messenger

The meeting broke up into groups to discuss the purposes of the groups and it was agreed that these fell under four broad headings

1. To liaise with relevant organisations, in particular Roy Castle Lung Cancer Foundation and pharma' to raise funds for the purposes of the UK ALK group
2. To provide an information resource for UK patients, in particular access to information about latest developments and clinical trials
3. To identify and locate UK ALK patients and to offer support and guidance on the location of UK ALK specialists and services
4. To influence decision makers, e.g. NICE, NHS, DVLA and raise awareness of ALK, particularly amongst the medical profession so as to promote the best treatment for patients.

The Next Steps

1. It was agreed that the next meeting would be held in Manchester on 13 October
2. Deshani offered to check whether one of the Manchester Hiltons would be a suitable venue for the meeting.
3. Graham to prepare a report on setting up a charity
4. Debra to set up a FB page