

# ALK POSITIVE UK – PATIENT FORUM

Radisson Blu Hotel, Birmingham

7 September 2019

## **Present**

28 Patients and 24 Carers

### **1. Welcome**

Debra Montague, Chair of ALK Positive Lung Cancer (UK), welcomed everyone to the largest gathering of ALK+ patients, family and friends in the world outside the USA.

### **2. NICE**

Deb gave a brief description of the assessment process used by the National Institute for Health and Care Excellence (NICE). The Scottish Medicines Consortium (SMC) uses a similar but independent process in Scotland. During discussion it was noted that pharmaceutical companies will make commercial judgements when setting the terms of their application and NICE can give approval only within those terms. Copy of Deb's slides are available on request.

### **3. Open Forum**

There then followed nearly two hours of wide-ranging discussion with patients giving an outline of their experiences. Deb thanked all those who had spoken, particularly those who were attending the Forum for the first time.

### **4. Dr Shobhit Bajjal – Consultant Oncologist**

Dr Bajjal spoke about the clinical utility of liquid biopsy in managing lung cancer. He described the advantages and disadvantages of both tissue and liquid biopsies. Cancer cells may not be present throughout a tumour and a tissue biopsy may give a false negative, depending on where the needle is put. He spoke about biomarker monitoring and next generation sequencing. These could be used to monitor the effectiveness of treatment but it is not currently clear how the information would be used. He said that there were exciting developments in hand but it might be some time before they are introduced.

Dr Bajjal answered questions and was thanked for his enlightening talk. Slides available on request.

### **5. Dr Rob Hurry – General Practitioner**

Dr Hurry said the incidence of lung cancer is reducing but is increasing in fit younger people, particularly women. 90% are diagnosed at stage. This picture could be improved by

Prevention  
Screening  
Latest diagnostics and investigations  
Elimination of misconceptions  
Personalised treatment access to trials

He said that genetic sequencing will become standard in the near future. Combined treatments, eg chemotherapy and TKI, is being investigated. He advised all patients to stay fit to tolerate any chemotherapy that they may need.

Dr Hurry elaborated on the work that he is undertaking on developing a Primary Care Alert Platform, the purpose of which would be to alert GP to consider the possibility of lung cancer when certain symptoms are present, even in patients who are not typical candidates.

Dr Hurry was thanked for his presentation. Slides available on request.

## **6. Report from the Trustees**

Debra gave an illustrated presentation which showed

- the principal aims of the charity are (a) to enable all ALK positive patients in the UK to share experiences and to give and receive mutual support, (b) to be an information resource and (c) to advocate on behalf of ALK positive patients
- the 14 organisations with which we have developed links
- the growth in membership from 45 to 215 in just over 12 months
- that doctors and nurses are the principal source of referrals to the charity
- the Team of Trustees and advisors

Slides available on request

Debra said that shortly we are going to launch a comprehensive survey of members to capture real experiences of real patients in the real world and that she hoped that every member would participate.

## **7. Close**

Debra thanked everyone for attending and said that the next meeting is likely to be held in London in February