



ALK Positive Lung Cancer (UK)

A Registered Charity (1181171)

www.alkpositive.org.uk

Changing Perceptions of Lung Cancer

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Driving and Lung Cancer

1. About 4% of lung cancer patients are ALK-positive, ie have a rearrangement of the Anaplastic Lymphoma Kinase gene. The majority of patients are female (68%), non-smokers (70%), median age of 50 years at diagnosis and diagnosed at stage 4 (85%).
2. In recent years, there have been remarkable developments in the treatment of this condition. Molecular targeted therapy drugs known as Tyrosine Kinase Inhibitors (TKIs) are now available to delay the progression of the condition. The life expectancy of ALK-positive patients has increased substantially in recent years and the mean life expectancy is now 6.8 years. It is not unreasonable to expect that this life-expectancy will continue to increase. These modern drugs enable patients to live a reasonably normal life, including caring for family and working, for many years.
3. About 20% of patients will have brain metastases at diagnosis and about 60% will develop brain metastases during their treatment. The Charity recently carried out a survey of its members and 38 respondents reported that they have or have had brain metastasis. 84% of the 38 had never had a seizure. Of those who had experienced a seizure, 100% reported that the seizures had occurred prior to the diagnosis of brain metastases and hence the start of treatment by TKIs. None reported a seizure following commencement of treatment.
4. **The conclusion to be drawn from this survey is that current molecular targeted treatments are very effective at preventing seizures.**

5. ALK-positive patients must notify the DVLA if they are diagnosed with brain metastases and must surrender their driving licences. Relicensing may be considered 1 year after commencement of the targeted therapy if there is clinical and imaging evidence of disease stability or improvement with no deterioration both intracranially or elsewhere in the body.

6. It is the view of the Charity that current DVLA rules are unnecessarily harsh on ALK-positive patients receiving modern treatments and are out of step with the rules applied to persons suffering from the neurological effects of diabetes and epilepsy, where drugs are also used to control their conditions.

7. Remaining active and being able to drive is very important to our members. A driving licence is a lifeline for many people. The licence enables mobility, independence, employment and freedom particularly for those who live in rural locations without immediate access to any form of public transport.

8. **We are satisfied that, based on the evidence of the effectiveness of modern treatments, the DVLA should commission a report by currently practising leading consultant oncologists who are expert in the field of ALK-positive lung cancer to review the current rules and, taking into account the rules for diabetes and epilepsy, to establish if there is sufficient clinical evidence for the following changes to be made –**
 - a. **Reducing the period before relicensing can be considered to 6 months supported by clinical and imaging evidence of disease stabilisation or improvement from a minimum of two periodic scans,**

 - b. **Removing reference to disease progression elsewhere in the body as a condition before relicensing can be considered**

 - c. **Recognising that some patients may receive treatment via both modern radiation methods (eg SRS, Cyber/Gammaknife etc) and targeted therapy and that, in such cases, rules relating to targeted therapy will apply.**

Debra Montague Chairman	Rebecca Stebbings Communications	Susan Eastwood Research	Angela Field Fundraising	Graham Lavender Secretary & Treasurer
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