Supporting patients with ocular melanoma

www.ocumeluk.org

[redacted]

24th March 2014

[redacted]

Re: Ipilimumab for previously untreated advanced (unresectable or metastatic) melanoma

Further to our recent appraisal of the consultation document for the above guideline, please ask the committee to consider the following points from OcuMel UK pertaining to patients with ocular melanoma.

Existing guidelines for ocular melanoma

It has been our understanding that NICE will not be producing guidance on ocular melanoma as it is too rare (6/7 per million). Therefore we have been working with a group of experts since April 2012 to create UK guidelines for ocular melanoma.

The chair of the group is Dr Paul Nathan and the project manager is Nancy Turnbull who can be contacted via om.guideline@gmail.com. The process has been funded by Melanoma Focus and the first draft is due to be sent for NICE accreditation on 1st April 2014.

Ocular melanoma is not included in the above NICE guideline

OcuMel UK would like the committee to note that ocular melanoma is an orphan disease with no recognised treatment. It is *genetically different* to cutaneous melanoma and therefore it is extremely unlikely that a UK ocular melanoma patient will have access to an immunotherapy trial in the near future.

We understand that you were not able to include ocular melanoma patients in your guidance as you have to align with the evidence that was presented to you by the manufacturer. However, if you do not mention ocular melanoma at all, it will have a significant impact on ocular melanoma patients. It is very important to OcuMel UK that you are aware of this.

If you do not make it *explicitly* clear that you have not included ocular melanoma patients, a medical oncologist seeing only one or two ocular melanoma patients a year will simply treat them in the same way as he does his cutaneous patients. If *you* do not make a distinction, the *physicians* will not make a distinction. However, the drugs company obviously *did* make a distinction by excluding ocular melanoma patients from latter trials.

Our request

OcuMel UK would like to see it specified in the recommendations that ocular melanoma *was not considered* during the drafting of these guidelines.

We would like the recommendation from NICE to be a "common sense" one – i.e. that patients with ocular melanoma should be referred to a medical oncologist specialising in their disease.

When the ocular melanoma UK guidelines mentioned above are completed, we would also ask that you make it clear there are alternative guidelines for ocular melanoma patients and provide a link to the relevant guidance.

If you have any questions or need any further information, please do not hesitate to contact me on 01276 682190.

Yours sincerely