cuMelUK

*United Against Ocular Melanoma Cancers*

The 21st of September 2023 Dr Mark Chakravarty

Lead non-executive director for appeals National Institute for Health and Care Excellence 2nd Floor, 2 Redman Place

London, E20 1JQ

Dear Dr Chakravarty,

We write to clarify & elaborate on the points raised in our letter dated the 31st of August.

It is widely accepted that people with uveal melanoma progress very quickly after metastases are found and that the current treatment options are ineffective. Their quality of life however is high until the very end. We have been supporting people in this situation for twelve years and have known and supported hundreds of patients and loved ones through the advanced stages of this disease.

We acknowledge our experience with this drug anecdotal, but the decision not to allow a drug for people with such an ultra-rare and aggressive cancer seems unfair and unreasonable as people will be left with no alternative chance of treatment. The methodology used in this appraisal also seems unreasonable as this is such a rare condition.

An example is the ERG's recommendation modelling using monthly best supportive care costs. This is a disease with extremely limited data on the care needs of someone with advanced uveal melanoma. Due to the rarity, the committee generally lacks understanding about this condition, and the ERG did not appear to consult with appropriate experts to get the information required to make informed decisions.

There are many uncertainties with rare cancers such as this, which have been outlined throughout this appraisal. Each of these uncertainties in silo may have a limited impact on the cost-effectiveness, but accumulatively, they result in these models not capturing what we see in real life.

Uveal melanoma has been granted as an orphan disease in the EU. Countries such as Austria, Belgium, France, Finland, Germany, Italy, Switzerland and the US have already approved using Tebentafusp, which allows their citizens a real chance of living well with uveal melanoma. The impact of this negative decision is devastating as they can now not access the only drug shown to improve survival. We believe this process has been unreasonable and unfair, and this must be reappraised.

We look forward to hearing from you soon on each of these points. Yours sincerely,

**For and on behalf of OcuMel UK**

1

OcuMel UK, 139 Langley Road, Slough, Berkshire SL3 7DZ. Charity Registered in England No. 1147506

**Helpline:** 0300 790 0512 **Telephone:** 01753 357771 **Email:** jo@omuk.info