

sent by email:

Mr John Chamberlayne  
BPA Chairman  
British Porphyria Association  
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3 July 2018

Dear Mr Chamberlayne

**Final Evaluation Determination: Afamelanotide for treating erythropoietic protoporphyria (EPP)**

Thank you for your letter of 28 June and your further observations on your appeal grounds 2.2 and 2.3.

**Ground 2 point 2**

On reflection and considering the additional points you make, I agree that the question of whether, the ERG economic model remained a decision aid that it was reasonable to use in the light of the evidence submitted during the appraisal should be put to an appeal panel.

**Ground 2 point 3**

I still do not think that reasonableness requires an ERG to engage with patients in developing an economic model. In practice the points that you want to make under this heading would largely fall into your ground 2.2 in any event, because the point is not so much that the ERG model was unusable at the outset, but that in light of what patient and clinical experts were saying during the appraisal it should have been realised to be unusable by the time of the final decision. As I think you can make these points under point 2.2, and as I think there is no

prospect that an appeal panel could find that there was an obligation to involve patients and others in the creation of an economic model, I will not refer this point on.

Therefore your valid appeal points are 2.1 and 2.2.

Yours sincerely

Dr Rosie Benneyworth  
Vice Chair  
National Institute for Health and Care Excellence