



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

27<sup>th</sup> June 2018

Dear Dr Benneyworth,

**Final Evaluation Determination: afamelanotide for treating erythropoietic protoporphyria**

Thank you very much for your letter of 14<sup>th</sup> June setting out your initial review of the points of appeal that the British Association of Dermatologists (BAD) has raised.

We acknowledge that your initial review finds the following points raised by the BAD are valid for appeal, as referenced in your letter:

- 2.1 "clinical trials suggest small benefits with afamelanotide"
- 2.4 "the committee took into account the full range of factors"
- 2.5 "the committee concluded that the trials had shown relatively small benefit"

We understand that an appeal panel cannot receive new evidence.

We still strongly believe, and refer to evidence presented in our previous submissions, that the further points below remain valid to pursue:

- 2.3 "cannot be recommended for routine funding in the NHS"
- 2.6 "it (DLQI) has been shown to be sensitive to the impact of EPP on people with the condition"
- 2.7 "the committee considered that the MAA would not have the plausible potential to reduce the uncertainties identified"
- 2.8 "it (the company) was willing to enter into discussions with NHS England"

We would still intend to defend these at the appeal and would be grateful therefore if you would reconsider, regarding the inclusion of these points in the appeal.

Thank you very much for your attention.

Yours sincerely,

Dr Pamela McHenry, Professor Lesley Rhodes and Dr Robert Sarkany  
On behalf of the British Association of Dermatologists