

Highly Specialised Technologies Evaluation Committee Meeting

Minutes: Confirmed

Date and Time: Tuesday 20 February 2018

Venue: National Institute for Health and Care Excellence
Level 1A, City Tower
Piccadilly Plaza
Manchester
M1 4BT

Present:	1. Dr Peter Jackson	Present for all notes
	2. Prof Ron Akehurst	Present for all notes
	3. Dr Ayesha Ali	Present for all notes
	4. Sotiris Antoniou	Present for all notes
	5. Sarah Davis	Present for all notes
	6. Stuart Davies	Present for all notes
	7. Jeremy Manual	Present for all notes
	8. Francis Pang	Present for all notes
	9. Linn Phipps	Present for all notes
	10. Dr Mark Sheehan	Present for all notes
	11. Dr Glenda Sobey	Present for all notes
	12. Professor Lesley Stewart	Present for all notes

In attendance:

Meindert Boysen	Programme Director, National Institute for Health and Care Excellence	Present for all notes
Sheela Upadhyaya	Associate Director, National Institute for Health and Care Excellence	Present for all notes
Joanne Ekeledo	Project Manager, National Institute for Health and Care Excellence	Present for all notes
Aminata Thiam	Technical Analyst, National Institute for Health and Care Excellence	Present for all notes
Raisa Sidhu	Technical Adviser, National Institute for Health and Clinical Excellence	Present for all notes

Mandy Tonkinson	Administrator, National Institute for Health and Clinical Excellence	Present for all notes
Antony Fearn	Patient Expert, nominated by The British Porphyria Association (BPA)	Present for notes 5 to 14
Jo Lord	ERG representative, Southampton Health Technology Assessments Centre	Present for notes 5 to 14
Edmund Jessop	NHS England	Present for notes 5 to 14
Professor Lesley Rhodes	Clinical Expert, nominated by Clinuvel and British Association of Dermatologists (BAD)	Present for notes 5 to 14
Dr Robert Sarkany	Clinical Expert, nominated by British Association of Dermatologists (BAD)	Present for notes 5 to 14
Jonathan Shepherd	ERG representative, Southampton Health Technology Assessments Centre	Present for notes 5 to 14
Dr Geoff Sloan	Patient Expert, nominated by The British Porphyria Association (BPA)	Present for notes 5 to 14

Non-public observers:

Julianah Adegbebisoye	Business Analyst, National Institute for Health and Clinical Excellence	Present for all notes
Helen Barnett	Editor, National Institute for Health and Clinical Excellence	Present for all notes
Kerry Oakford	Digital Costing Analyst, National Institute for Health and Clinical Excellence	Present for all notes
Darryl Quantz	NHS Public Health Trainee	Present for all notes

Karen Samuels	All Wales Therapeutics and Toxicology Centre	Present for all notes
Lulieth Torres	Technical Analyst, National Institute for Health and Clinical Excellence	Present for all notes

Notes

Welcome

1. The Chair welcomed all members of the Committee and other attendees present to the meeting. The Chair reviewed the agenda and timescales for the meeting, which included the evaluations of afamelanotide for treating erythropoietic protoporphyria.
2. The Chair informed the Committee of the non-public observers at this meeting: Julianah Adegbemisoye, Helen Barnett, Kerry Oakford, Darryl Quantz, Karen Samuels and Lulieth Torres
3. Apologies were received from Carrie Gardner and Dr Shehla Mohammed.

Any other Business

4. None

Evaluation of afamelanotide for treating erythropoietic protoporphyria.

Part 1 – Open session

5. The Chair welcomed the invited experts: Antony Fearn, Edmund Jessop, Professor Lesley Rhodes, Jo Lord, Dr Robert Sarkany, Jonathan Shepherd and Dr Geoff Sloan to the meeting and they introduced themselves to the Committee.
6. The Chair welcomed company representatives from Clinuvel Pharmaceuticals to the meeting.
7. The Chair asked all Committee members to declare any relevant interests
 - 7.1. All declared that they knew of no personal specific financial interest, personal non-specific financial interest, non-personal specific financial interest, non-personal non-specific financial interest, personal specific family interest or personal non-specific family interest for any of the technologies to be considered as part of the evaluation of afamelanotide for treating erythropoietic protoporphyria.
8. The Chair asked all NICE Staff to declare any relevant interests.
 - 8.1. All declared that they knew of no personal specific financial interest, personal non-specific financial interest, non-personal specific financial interest, non-personal non-specific financial interest, personal specific family interest or personal non-specific family interest for any of the technologies to be considered as part of the evaluation of afamelanotide for treating erythropoietic protoporphyria.

9. The Chair asked all other invited guests (assessment group/ERG and invited experts, not including observers) to declare their relevant interests.
 - 9.1. Antony Fearn, Edmund Jessop, Jo Lord, Dr Robert Sarkany, Jonathan Shepherd and Dr Geoff Sloan declared that they knew of no personal specific financial interest, personal non-specific financial interest, non-personal specific financial interest, non-personal non-specific financial interest, personal specific family interest or personal non-specific family interest for any of the technologies to be considered as part of the evaluation of afamelanotide for treating erythropoietic protoporphyria.
 - 9.2. Prof Lesley Rhodes declared a non-personal financial interest as she directs a research programme on sunlight effects on health with funding from numerous organisations.
 - 9.2.1. It was agreed that this declaration would not prevent Prof Lesley Rhodes from participating in this section of the meeting
10. The Chair introduced the key themes arising from the consultation responses to the Evaluation Consultation Document (ECD) received from consultees, commentators and through the NICE website.
11. The Chair asked the company representatives whether they wished to comment on any matters of factual accuracy.
12. The Chair explained that “representatives of the press and other members of the public be excluded from the remainder of this meeting having regard to the confidential nature of the business to be transacted, publicity on which would be prejudicial to the public interest” (Section 1(2) Public Bodies (Admission to Meetings) Act 1960)” and all public attendees left the meeting.
13. The Chair then thanked the experts and company representatives for their attendance, participation and contribution to the evaluation and they left the meeting.

Part 2 – Closed session

14. Discussion on confidential information continued. This information was supplied by the company.
15. The Committee continued to discuss the clinical and cost effectiveness of afamelanotide for treating erythropoietic protoporphyria.
16. The Committee instructed the technical team to prepare the Evaluation Consultation Document (ECD) or Final Evaluation Determination (FED) in line with their decisions.

Date, time and venue of the next meeting

17. Tuesday 20 March 2018, National Institute for Health and Care Excellence, Level 1A, City Tower, Piccadilly Plaza, Manchester M1 4BT.