

Highly Specialised Technologies Evaluation Committee Meeting

Minutes: Confirmed

Date and Time: Thursday 17 August 2017, 10:35am to 2:00pm

Venue:
Holiday Inn Manchester
25 Aytoun Street
Manchester
M1 3AE

Present:	1. Peter Jackson, Chair 2. Ayesha Ali 3. Sotiris Antoniou 4. Sarah Davis 5. Stuart Davies 6. Carrie Gardner 7. Jeremy Manuel 8. Linn Phipps 9. Mark Sheehan 10. Lesley Stewart	Present for all notes Present for all notes
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In attendance:

Meindert Boysen	Programme Director, National Institute for Health and Care Excellence	Present for all notes
Dr Alex Broomfield	Clinical Expert on behalf of Dr Simon Jones, nominated by Willink Biochemical Genetics Unit	Present for notes 1 to 13
Joanne Ekeledo	Project Manager, National Institute for Health and Care Excellence	Present for all notes
Dr Mark Friedman	Senior Medical Director, Alexion	Present for notes 1 to 15
Suzy Heafield	NHS England, Commissioning Expert	Present for notes 1 to 15
Edmund Jessop	NHS England, Commissioning Expert	Present for notes 1 to 15

Raisa Sidhu	Technical Advisor, National Institute for Health and Care Excellence	Present for all notes
Sophie Thomas	Patient Expert, nominated by the Mucopolysaccharide Society (MPS Society)	Present for 1 to 13
Mandy Tonkinson	Administrator, National Institute for Health and Care Excellence	Present for all notes
Sara Trafford Jones	VP and General Manager, Alexion	Present for notes 1 to 15
Sheela Upadhyaya	Associate Director, National Institute for Health and Care Excellence	Present for all notes
Heidi Wagner	Senior Vice President	Present for notes 14 to 13
Ian Watson	Technical Advisor, National Institute for Health and Care Excellence	Present for all notes

Non-public observers:

Heidi Livingstone	Public Involvement Programme, National Institute for Health and Care Excellence	Present for all notes
Rosie Lovett	Senior Scientific Advisor, National Institute for Health and Care 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 evaluation of **sebelipase alfa for treating lysosomal acid lipase deficiency**.
2. The Chair informed the Committee of the non-public observers at this meeting: Heidi Livingstone and Rosie Lovett.

3. Apologies were received from Professor Ron Akehurst, Dr Vincent Kirkbride, Francis Pang, Dr Glenda Sobey and Dr Shehla Mohammed.

Any other Business

4. None

Evaluation of sebelipase alfa for treating lysosomal acid lipase deficiency

Part 1 – Open session

5. The Chair welcomed the invited experts: Dr Alex Bloomfield and Sophie Thomas to the meeting and they introduced themselves to the Committee.
6. The Chair welcomed company representatives from Alexion Pharma UK to the meeting.
7. The Chair asked all Committee members to declare any relevant interests
 - 7.1. Ayesha Ali, Sotiris Antoniou, Sarah Davis, Stuart Davies, Carrie Gardner, Linn Phipps, Mark Sheehan, Lesley Stewart 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 sebelipase alfa for treating lysosomal acid lipase deficiency.
 - 7.2. Jeremy Manuel declared a non-personal non-specific financial interest as part of his interaction with the MPS Society on other matters.
 - 9.2.1 It was agreed that this declaration would not prevent Jeremy Manuel from participating in this section of the meeting.
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 sebelipase alfa for treating lysosomal acid lipase deficiency.
9. The Chair asked all other invited guests (assessment group/ERG and invited experts, not including observers) to declare their relevant interests.
 - 9.1. 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 sebelipase alfa for treating lysosomal acid lipase deficiency.
10. The Chair introduced the key evidence and issues for consideration by the committee, including additional information submitted by the company..

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 clinical and patient experts for their attendance, participation and contribution to the evaluation and they left the meeting.

Part 2a – Closed session (Company and Committee Present and Commissioning experts only)

14. Discussion on confidential information continued. This information was supplied by the company.
15. The Chair then thanked the company and commissioning experts for their attendance, participation and contribution to the evaluation and they left the meeting.

Part 2b – Closed session

16. The Committee continued to discuss the clinical and cost effectiveness of sebelipase alfa for treating lysosomal acid lipase deficiency.

Date, time and venue of the next meeting

17. Thursday 28 September at 10:00am at National Institute for Health and Care Excellence, Level 1A, City Tower, Piccadilly Plaza, Manchester M1 4BT.