

## Highly Specialised Technologies Evaluation Committee Meeting

**Minutes:** **Confirmed**

**Date and Time:** Tuesday 22 March 2016 10.00am - 4.00pm

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

<b>Present:</b>	1. Peter Jackson (Chair) 2. Ron Akehurst 3. Sotiris Antoniou 4. Sarah Davis 5. Jonathan Howell 6. Vincent Kirkbride 7. Francis Pang 8. Linn Phipps 9. Mark Sheehan 10. Anthony Wierzbicki	Present for all notes Present for all notes Present for notes 11 to 17 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
Sheela Upadhyaya	Associate Director, National Institute for Health and Care Excellence	Present for all notes
Jenna Dilkes Leanne Wakefield	Project Manager, National Institute for Health and Care Excellence	Present for all notes
Mary Hughes	Technical Analyst, National Institute for Health and Care Excellence	Present for all notes
Linda Landells	Technical Adviser, National Institute for Health and Care Excellence	Present for all notes

Anoukh van Giessan	Kleijnen Systematic Reviews	Present for notes 1 to 14
Rob Riemsma	Kleijnen Systematic Reviews	Present for notes 1 to 14
Emma Harvey	Alexion Pharma UK	Present for notes 1 to 14
Sara Trafford Jones	Alexion Pharma UK	Present for notes 1 to 14
Simon Jones	Clinical Expert	Present for notes 1 to 14
Amjad Akhtar	Patient Expert	Present for notes 1 to 14
Stuart Lancaster	Patient Expert	Present for notes 1 to 14
Sophie Thomas	Patient Expert	Present for notes 1 to 14
Edmund Jessop	NHS England	Present for notes 1 to 14

### **Non-public observers:**

Karen Carter	Technical Analyst, NICE	Present for all notes
Ann Greenwood	Editor, NICE	Present for all notes
Lydia Shears	Public Involvement Adviser, NICE	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: Karen Carter, Ann Greenwood and Lydia Shears.
3. Apologies were received from Steve Brennan, Trevor Cole, Jeremy Manuel and Lesley Stewart.

#### **Any other Business**

4. None.

#### **Notes from the last meeting**

5. The minutes from the meeting which took place on 17 February 2016 were agreed.
6. **Evaluation of Sebelipase alfa for treating lysosomal acid lipase deficiency**

## **Part 1 – Open session**

7. The Chair welcomed the invited experts: Anoukh van Giessan, Rob Riemsma, Simon Jones, Amjad Akhtar, Stuart Lancaster, Sophie Thomas and Edmund Jessop to the meeting and they introduced themselves to the Committee.
8. The Chair welcomed company representatives from Alexion Pharma UK to the meeting.
9. The Chair asked all Committee members to declare any relevant interests
  - 9.1. Peter Jackson, Sotiris Antoniou, Sarah Davis, Jonathan Howell, Vincent Kirkbride and Mark Sheehan 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.
  - 9.2. Anthony Wierzbicki declared a non-personal specific financial interest due to his role as Clinical Investigator for Trust Hospital on studies of lipid lowering compounds for Merck; Pfizer and Amgen and Clinical Registry Investigator for Chiesi for lipid lowering drugs.
    - 9.2.1 It was agreed that this declaration would not prevent Anthony Wierzbicki from participating in the meeting.
  - 9.3. Linn Phipps declared a personal non-specific financial interest due to her role as Patient and Public Voice Representative on NHS England's Clinical Priorities Advisory Group (CPAG)
    - 9.3.1 It was agreed that this declaration would not prevent Linn Phipps from participating in the meeting.
  - 9.4. Francis Pang declared a personal non-specific financial interest due to his role within the healthcare industry.
    - 9.4.1 It was agreed that this declaration would not prevent Francis Pang from participating in the meeting.
  - 9.5. Ron Akehurst declared a personal non-specific financial interest due to his role as Strategic Director within the healthcare industry.
    - 9.5.1 It was agreed that this declaration would not prevent Ron Akehurst from participating in the meeting.
10. The Chair asked all NICE Staff to declare any relevant interests.
  - 10.1. Amjad Akhtar, Stuart Lancaster, Sophie Thomas, Edmund Jessop, Anoukh van Giessan, Manuela Joore and Rob Riemsma 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.

10.2. Simon Jones declared a personal specific financial interest due to his role as Clinical Trial Investigator and consultancy advice to Alexion Pharma UK for Sebelipase alfa for treating lysosomal acid lipase deficiency.

10.2.1. It was agreed that this declaration would not prevent Simon Jones from participating in this section of the meeting.

11. 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
12. The Chair asked the company representatives whether they wished to comment on any matters of factual accuracy.
13. 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.
14. 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**

15. Discussion on confidential information continued. This information was supplied by the company.
16. The Committee continued to discuss the clinical and cost effectiveness of sebelipase alfa for treating lysosomal acid lipase deficiency.
17. The Committee instructed the technical team to prepare the post meeting documentation in line with their decisions.