

## Highly Specialised Technologies Evaluation Committee Meeting

**Minutes:** Confirmed

**Date and Time:** Wednesday 19 April 2017, 10am to 12:45pm

**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. Ayesha Ali 3. Sotiris Antoniou 4. Sarah Davis 5. Carrie Gardner 6. Shehla Mohammed 7. Linn Phipps 8. Mark Sheehan 9. Glenda Sobey 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
Sheela Upadhyaya	Associate Director, National Institute for Health and Care Excellence	Present for all notes
Jenna Dilkes	Project Manager, National Institute for Health and Care Excellence	Present for all notes
Raisa Sidhu	Technical Advisor, National Institute for Health and Care Excellence	Present for all notes
Mandy Tonkinson	Administrator, National Institute for Health and Clinical Excellence	Present for all notes
Philip Morgan	ERG Representative	Present for notes 1 to 14

Tanya Collin-Histed	Patient Expert, Nominated by Gauchers Association	Present for notes 1 to 14
Professor Tim Cox	Clinical Expert, Nominated by Gauchers Association and Genzyme	Present for notes 1 to 14
Clare Grant	Head of Health Outcomes, Genzyme	Present for notes 1 to 14
Daniel Franks	Associate Director, Medical Director, Rare Disease, Genzyme	Present for notes 1 to 14

**Non-public observers:**

Heidi Livingstone	Public Involvement Programme National Institute for Health and Care Excellence	Present for all notes
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**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 **Eliglustat for treating type 1 Gaucher disease**.
2. The Chair welcomed Ayesha Ali to her first meeting as a member of the Evaluation Committee.
3. The Chair informed the Committee of the non-public observers at this meeting: Heidi Livingstone.
4. Apologies were received from Ron Akehurst, Vincent Kirkbride, Jeremy Manuel and Francis Pang.

**Any other Business**

5. None

**Eliglustat for treating type 1 Gaucher disease**  
**Part 1 – Open session**

6. The Chair welcomed the invited experts and assessment group representatives: Tanya Collin-Histed, Tim Cox and Philip Morgan to the meeting and they introduced themselves to the Committee.

7. The Chair welcomed company representatives from Genzyme to the meeting.
8. The Chair asked all Committee members to declare any relevant interests
  - 8.1. Ayesha Ali, Sarah Davis, Carrie Gardner, Peter Jackson, Shehla Mohammed, Linn Phipps, Mark Sheehan and Glenda Sobey 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 eliglustat for treating type 1 Gaucher disease.
  - 8.2. Sotiris Antoniou declared a personal non-specific financial interest due to involvement with an unrelated product with Sanofi who are now part of Genzyme.
    - 8.2.1. It was agreed that this declaration would not prevent Sotiris Antoniou from participating in this section of the meeting.
  - 8.3. Linn Phipps declared a personal non-specific financial interest from her role as Patient & Public Representative for Yorks & Humber SCOG.
    - 8.3.1. It was agreed that this declaration would not prevent Linn Phipps from participating in this section of the meeting.
  - 8.4. Lesley Stewart declared a non-personal specific non-financial interest as other members of York acted as ERG for this topic.
    - 8.4.1. It was agreed that this declaration would not prevent Lesley Stewart from participating in this section of the meeting.
  - 8.5. Ron Akehurst was absent due to conflicts. Ron Akehurst declared a personal non-specific financial interest due to his relationship to the company of the topic under evaluation.
    - 8.5.1. It was agreed that this declaration would prevent Ron Akehurst from participating in the meeting.
  - 8.6. Francis Pang was absent due to conflicts. Francis Pang declared a personal non-specific financial interest due to his relationship to the company of the topic under evaluation.
    - 8.6.1. It was agreed that this declaration would prevent Francis Pang from participating in the meeting.
  - 8.7. Jeremy Manuel was absent due to conflicts. Jeremy Manuel declared a personal specific financial interest as he is the former founder, Director and Chairman of Gauchers Association.
    - 8.7.1. It was agreed that this declaration would prevent Jeremy Manuel from participating in the meeting.
9. The Chair asked all NICE Staff to declare any 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 of Eliglustat for treating type 1 Gaucher disease.

10. The Chair asked all other invited guests (assessment group/ERG and invited experts, not including observers) to declare their relevant interests.
  - 10.1. Philip Morgan declared that he 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 Eliglustat for treating type 1 Gaucher disease.
  - 10.2. Tim Cox declared a personal specific financial interest due to his role with Clinical Trials, Advisory Boards and Consultancy in relation to eliglustat for treating type 1 Gaucher disease.
    - 10.2.1. It was agreed that this declaration would not prevent Tim Cox from participating in this section of the meeting.
  - 10.3. Tanya Collin-Histed declared a personal specific financial interest due to her role as a Consultant in relation to eliglustat for treating type 1 Gaucher disease and due the Gauchers Association receiving grants for patient support programmes in 2015/16 from Shire and Genzyme.
    - 10.3.1. It was agreed this declaration would not prevent Tanya Collin-Histed 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.
15. **Part 2 – Closed session**
16. Discussion on confidential information continued.
17. The Committee continued to discuss the clinical and cost effectiveness of Eliglustat for treating type 1 Gaucher disease
18. The Committee instructed the technical team to prepare the Evaluation Consultation Document or Final Evaluation Determination (FED) in line with their decisions.
19. **Date, time and venue of the next meeting**
20. Thursday 25 May from 10:00am at National Institute for Health and Care Excellence, Level 1A, City Tower, Piccadilly Plaza, Manchester M1 4BT.