NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Centre for Health Technology Evaluation

# Highly Specialised Technologies Evaluation Committee (HSTEC) meeting minutes

**Minutes:** Confirmed

**Date:** Thursday 05 September 2024

**Location:** Via Zoom

## Attendees

Committee members present

1. Dr Paul Arundel (Chair) Present for all items
2. Professor Iolo Doull (Vice Chair) Present for all items
3. Annett Blochberger Present for all items
4. Emtiyaz Chowdhury Present for all items
5. Sarah Davis Present for all items
6. Tina Garvey Present for all items
7. Professor Jonathan Ives Present for all items
8. Stuart Mealing Present for all items
9. Sara Payne Present for all items
10. Professor Ed Wilson Present for all items

NICE staff (key players) present

Jacoline Bouvy, Programme Director, Medicines Evaluation Present for all items

Jasdeep Hayre, Associate Director Present for all items

Celia Mayers, Project Manager Present for all items

Joanna Richardson, Health Technology Assessment Adviser Present for all items

Ross Wilkinson, Health Technology Assessment Analyst Present for all items

External assessment group representatives present

Ana Duarte, Centre for Reviews and Dissemination and Centre for Health Economics - York Items 1 to 4.1.3

Mark Simmonds, Centre for Reviews and Dissemination and Centre for Health Economics - York Items 1 to 4.1.3

Clinical, Patient & NHS England experts present

Liz Brownnutt, Chief Executive Officer at Batten Disease Family Association (BDFA), patient expert nominated by BDFA Items 1 to 4.1.3

Lucy Carroll, Parent, patient expert nominated by BDFA Items 1 to 4.1.3

Gail Rich, Parent, patient expert nominated by BDFA Items 1 to 4.1.3

Paul Gissen, Clinical Professor in Paediatric Metabolic Medicine & Honorary Consultant, clinical expert nominated by BioMarin (company) and BDFA Items 1 to 4.1.3

Ayesha Ali, Medical Advisor, Highly Specialised Services, NHS England Present for all items

Sanjeev Patel, IMF clinical lead, NHS England Present for all items

*Please note that alongside the attendees listed in this document, there were additional NICE Staff present in this meeting. These attendees were not involved in the decision making or discussions.*

## Minutes

### Introduction to the meeting

* 1. The chair welcomed members of the committee and other attendees present to the meeting.
  2. The chair noted apologies from Angharad Shambler, Carrie Gardner, Dusko Ilic, Shehla Mohammed.

### News and announcements

* 1. The chair stated that it was Sarah Davis’ last meeting. The committee wished Sarah good luck for the future.
  2. The chair welcomed back Annett Blochberger who is attending her first meeting after maternity leave.

### Minutes from the last meeting

* 1. It was agreed that the minutes from the meeting on 15 August 2024 will be reviewed at the next meeting.

### Evaluation of cerliponase alfa for treating neuronal ceroid lipofuscinosis type 2 (review of HST12) [ID6145]

* 1. Part 1 – Open session
     1. The chair welcomed the invited experts, external assessment group representatives, members of the public and company representatives from BioMarin.
     2. The chair asked all committee members and experts, external assessment group representatives and NICE staff present to declare any relevant interests in relation to the item being considered. Declarations for this appraisal can be found on the Topic Register of Interest (TROI) on the topic webpage, [here](https://www.nice.org.uk/guidance/indevelopment/gid-hst10061).
     3. The Chair led a discussion of the consultation comments presented to the committee. This information was presented to the committee by the chair.
  2. Part 2 – Closed session (company representatives, clinical and patient experts, external assessment group representatives and members of the public were asked to leave the meeting)
     1. The committee then agreed on the content of the Draft Guidance (DG) or Final Draft Guidance (FDG). The committee decision was reached by consensus.
     2. The committee asked the NICE technical team to prepare the Draft Guidance (DG) or Final Draft Guidance (FDG) in line with their decisions.
* Further updates will be available on the topic webpage in due course: <https://www.nice.org.uk/guidance/indevelopment/gid-hst10061>.

### Date of the next meeting

The next meeting of the Highly Specialised Technologies Evaluation Committee (HSTEC) will be held on Thursday 10 October 2024 and will start promptly at 09:00am.