

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE
TUESDAY 22 OCTOBER 2024 (13:00-15:00)
THE ARCHBISHOPS ROOM, MILLBANK HOUSE, LITTLE COLLEGE STREET,
LONDON, SW1P 3SH; AND VIA ZOOM**

MEETING MINUTES

Present in person:

Lord Sharkey – **Chair, SHCA**
Baroness Chisholm – **Vice Chair, SHCA**
Baroness Sater – **Vice Chair, SHCA**

Andrew Brown – **Alexion**
Georgina Carr – **The Neurological Alliance**
Steve Cotterell – **MPS Society**
Deb Flanagan – **Gilead Sciences**
Vicky Hargreaves – **Novartis**
Ellie Kirkland – **Muscular Dystrophy UK**
Debra Morgan – **The Haemophilia Society**
Joe Smale – **Cystic Fibrosis Trust**

Secretariat:

Amelia Sunkaraneni – **SHCA Secretariat**
Henry Poust – **SHCA Secretariat**
Fenella Lloyd – **SHCA Secretariat**
Rennie Baxter – **SHCA Secretariat**

Present Via Zoom:

Samantha Barber – **Gene People**
Markus Bell – **Nerve Tumours UK**
Sarah Berry – **The British Society for Rheumatology**
Jade Bridger – **Takeda**
Liz Brownnutt – **Batten Disease Family Association (BDFA)**
Rich Collins – **GAIN**
Amy Capper – **Myeloma UK**
Laura Cook – **Cardiomyopathy UK**
Emma Cooper – **The Pituitary Foundation**
Kripen Dhrona – **British Polio Fellowship**
Sue Dimmock – **UKPIPS**
Jonathan Gibson – **Metabolic Support UK**
Jill Harkin – **Sanofi**
Lucy Hescott – **Johnson & Johnson Innovative Medicine UK**
Andrew Hollingsworth – **Vertex Pharmaceuticals**

Sara Hunt – **Alex, The Leukodystrophy Charity**
Jessica Jones – **National Kidney Federation**
Gillian McCarthy – **CLAPA**
Joella Melville – **Niemann-Pick UK**
Rachel Miller-Stainsby – **Myrovlytis Trust**
Maya Parkin – **Bliss**
Jane Paxton – **DC Action**
Alison Railton – **Kidney Research UK**
Lily-Rose Sharry – **Dementia UK**
Pooja Takhar – **Tuberous Sclerosis Association**
Chris Wingrove – **Amicus Therapeutics**
Hannah Winter – **Ipsen**

1. GUEST SPEAKER

Jack Turner, Deputy Director for Commercial Medicines Access Policy, Medicines Value & Access at NHS England (NHSE), spoke at the meeting.

Agreed: SHCA Secretariat to circulate the slides that Jack presented to members, following NHSE's approval. **As appropriate**

2. APOLOGIES

- John James – **Sickle Cell Society**
- Ben Leach – **Amicus Therapeutics**

3. MINUTES FROM THE LAST MEETING

Reported: The minutes of the last quarterly meeting on Wednesday 24 July 2024 were agreed and will be published on the SHCA's website. **Done**

4. MATTERS ARISING

Reported: As per notes on agenda.

5. KEY POLICY ISSUES

5.1 Policy update

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to consider wider opportunities to influence and engage with the Government's consultation on the 10 Year Health Plan. **As appropriate**

5.2 UK Rare Diseases Framework

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to follow-up with Department of Health and Social Care (DHSC) on the NHS Health Inequalities toolkit and circulate with members when it is published. **As appropriate**

Agreed: Members to share any evidence relevant to the National Institute for Health and Care Research's (NIHR) literature review on including rare diseases within the Core20PLUS5 programme for SHCA Secretariat to pass on to DHSC. **As appropriate**

5.3 Specialised commissioning reform

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to follow up with NHSE on securing a representative from an ICB in East of England to speak at an SHCA quarterly meeting in 2025. **As appropriate**

5.4 NICE update

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to follow up with John Spors, National Institute for Health and Care Excellence (NICE), with questions from members, including on timelines for NICE's research on how the public values severity following the severity modifier review. **As appropriate**

6. KEY ACTIVITY

6.1 UK Rare Diseases Framework survey

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to share draft report with members for their feedback. **November**

6.2 Delegation listening exercise

Reported: As per notes on agenda.

Agreed: Members to get in touch with the SHCA Secretariat with any reflections relevant to the delegation listening exercise. **As appropriate**

Agreed: SHCA Secretariat to continue listening exercise and publish short report. **December**

6.3 Ministerial engagement

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to follow up with Andrew Gwynne, Parliamentary Under Secretary of State for Public Health and Prevention, inviting him to attend as a guest speaker at a quarterly meeting in 2025. **As appropriate**

6.4 Annual membership survey

Reported: As per notes on agenda.

7. PLANS FOR 2025

7.1 Proposed objectives for 2025

Reported: As per notes on agenda.

7.2 Proposed activities

Agreed: Members approved the following plans for 2025:

- Mental health profiles
- Making the case for screening policy change
- Future commissioning
 - Delegation case studies
 - Toolkit for charities on how to engage
 - Transparency of data
- International comparisons on incorporating health inequalities in HTA
- One year on from NICE's patient involvement strategy
- 10-year plan for rare diseases
- Exploring the future of clinical trials for rare diseases
- Advocating for UK participation in European Reference Networks

Agreed: SHCA Secretariat to consider how to integrate developing a rare diseases organogram into 2025 planning. **As appropriate**

Agreed: Members to contact SHCA Secretariat with any further feedback or additions to the approved plans. **As appropriate**

8. APPROVAL OF 2025 PLANS AND SECRETARIAT

Agreed: Members approved the continuation of Incisive Health as the Secretariat. **All to note**

9. ANY OTHER BUSINESS

Eleven healthcare companies are Corporate Supporters of the Alliance. This entitles the companies to attend SHCA meetings and receive SHCA communications. The Alliance's policy positions, and work programme will, however, be solely determined by members.