

MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE
THURSDAY, 19 JUNE 2025 (11:00-13:00)
THE ARCHBISHOPS ROOM, MILLBANK HOUSE, LITTLE COLLEGE STREET,
LONDON, SW1P 3SH; AND VIA ZOOM

MEETING MINUTES

Present in person:

Lord Sharkey – **Chair, SHCA**
Baroness Keeley – **Vice Chair, SHCA**

Iain Armstrong – **Pulmonary Hypertension Association UK**
Liz Barnard – **Kidney Research UK**
Andy Barrick – **Multiple System Atrophy Trust**
Jeff Courtney – **Haemophilia Society**
Derralynn Hughes – **MPS Society**
Tenley Fuentes – **RAIRDA**
Ben Leach – **Amicus Therapeutics**

Secretariat:

Rennie Baxter – **SHCA Secretariat**
Ed McIntosh – **SHCA Secretariat**
Henry Poust – **SHCA Secretariat**
Amelia Sunkaraneni – **SHCA Secretariat**
Cerys Williams – **SHCA Secretariat**

Present via Zoom:

Sarah Bailey – **PINNT**
Samantha Barber – **Gene People**
Florence Barkats – **PCD Research**
Zac Barnett – **Sickle Cell Society**
Katie Begg – **Blood Cancer Alliance**
Lachlan Bruce – **Cleft Lip and Palate Association (CLAPA)**
Andrea Brown – **National Kidney Federation**
Lee-Ann Farrell – **Johnson & Johnson Innovative Medicine**
Jonathan Gibson – **Metabolic Support UK**
Rajwant Kaur Singh – **Children's Heart Foundation**
Joe Kirwin – **The Aplastic Anaemia Trust**
Olaolu Oloyede – **Novartis**
Patricia Osborne – **Brittle Bone Society**
Jane Paxton – **DC Action**
Charlotte Roberts – **Vertex**
Cristina Sarb – **Novartis**
Joe Smale – **Cystic Fibrosis Trust**

Victoria Solovieva – **PNH Support**
Pooja Takhar – **The Tuberous Sclerosis Association**
Susan Walsh – **Immunodeficiency UK**

1. APOLOGIES

- Baroness Sater – **SHCA Vice Chair**
- Liz Brownnutt – **Batten Disease Family Association**
- Kripen Dhrona – **The British Polio Fellowship**
- Glyn Hayes – **Spinal Injuries Association**
- Fiona Loud – **Kidney Care UK**
- Lewis Petty – **Spinal Injuries Association**
- Dharshana Sridhar – **Spinal Injuries Association**

2. MINUTES FROM THE LAST MEETING

Reported: The minutes of the last quarterly meeting on Thursday 20 March 2025 were agreed and will be published on the SHCA website. **Done**

3. MATTERS ARISING

4. KEY POLICY ISSUES

4.1 NHS reorganisation update

Reported: As per notes on agenda.

4.2 Specialised commissioning reform

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to share update on NHS England's (NHSE) review of direct commissioning functions upon publication. **As appropriate**

4.3 UK Rare Diseases Framework

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to follow-up with Ashley Dalton MP (Minister for Public Health and Prevention at the Department of Health and Social Care) to arrange a virtual session with SHCA members. **Ongoing**

Agreed: SHCA Secretariat to share the NHSE health inequalities toolkit with members once publicly available. **As appropriate**

5. KEY ACTIVITY

5.1 Engagement toolkit

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to keep the engagement toolkit under review and update accordingly with any changes to the specialised commissioning landscape. **As appropriate**

Agreed: SHCA members to share any insights they have from engaging at the local, regional or national level on specialised commissioning with the SHCA Secretariat for use in future versions of the engagement toolkit. **As appropriate**

5.2 Mental health stories

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to share the finalised version of the mental health stories report with members and relevant policymakers, including the parliamentary Joint Select Committee appointed to consider the ongoing Draft Mental Health Bill. **07.07.2025**

Agreed: SHCA Secretariat to share additional template materials to support members' social media activity around the report. **04.07.2025**

5.3 Collaboration with Genetic Alliance

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to share the virtual meeting link for the Genetic Alliance APPG meeting on Rare, Genetic and Undiagnosed Conditions meeting that the SHCA is supporting on. **Done**

5.4 Shaping the future of specialised commissioning

Reported: As per notes on agenda.

6. DISCUSSION ON POSITION STATEMENT

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to 1) update the position statement with feedback discussed at the meeting, 2) share with John Stewart (NHS England) ahead of an upcoming meeting and 3) finalise the document following the discussion from that meeting and any other feedback from SHCA members. **As appropriate**

Agreed: SHCA members to share any additional feedback on the position statement with the SHCA Secretariat. **As appropriate**

7. ANY OTHER BUSINESS

Ten 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.