

MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE
THURSDAY 23 OCTOBER 2025 (10:30-13:00)
COMMITTEE ROOM G, HOUSE OF LORDS, PALACE OF WESTMINSTER,
LONDON, SW1A 0PW, AND VIA MICROSOFT TEAMS

MEETING MINUTES

Present in person:

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

Iain Armstrong – **Pulmonary Hypertension Association UK**
Liz Barnard – **Kidney Research UK**
Zac Barnett – **Sickle Cell Society**
Andrew Brown – **Alexion**
Lachlan Bruce – **Cleft Lip and Palate Association (CLAPA)**
Dr Harriet Holme – **PCD Research**
Ellie Kirkland – **Muscular Dystrophy UK**
Rajwant Kaur Singh – **Children's Heart Federation**
Fiona Loud – **Kidney Care UK**
Debra Morgan – **The Haemophilia Society**
Cristina Sarb – **Novartis**
Bob Stevens – **MPS Society**
Lucy Vasiliou – **National Kidney Federation**
Elise Wilby – **Metabolic Support UK**

Secretariat:

Rennie Baxter – **SHCA Secretariat**
Tathan Harding Lloyd – **SHCA Secretariat**
Ed McIntosh – **SHCA Secretariat**
Henry Poust – **SHCA Secretariat**
Amelia Sunkaraneni – **SHCA Secretariat**

Present via Teams:

Baroness Sater – **Vice Chair, SHCA**
Samantha Barber – **Gene People**
Laura Clark – **Amicus Therapeutics**
Emma Cooper – **The Pituitary Foundation**
Lee-Ann Farrell – **Johnson & Johnson Innovative Medicine**
James Hammond – **Hepatitis C Trust**
Will Highfield – **Vertex**

Kerry Leeson-Beevers – **Alstrom Syndrome UK**
Catherine Lewis – **Alstrom Syndrome UK**
Samantha Lynch – **The Ehlers-Danlos Society**
Katharine McIntosh – **Cardiomyopathy UK**
Sam Mountney – **Neurological Alliance**
Nigel Nicholls – **Batten Disease Family Association**
Patricia Osborne – **Brittle Bone Society**
Jane Paxton – **DCAction**
Joe Smale – **Cystic Fibrosis Trust**
Victoria Solovieva – **PNH Support**
Chris Sotirelis – **UK Thalassaemia Society**
Pooja Takhar – **Tuberous Sclerosis Association**
Cathy Thompson – **Addison’s Disease Self-Help Group (ADSHG)**
Natalie Tuzcuoglu – **Amicus Therapeutics**
Dr Susan Walsh – **Immunodeficiency UK**
Catherine Wallis – **MS Society**
Chris Wingrove – **Amicus Therapeutics**

1. APOLOGIES

Andy Barrick – **Multiple System Atrophy Trust**
Lara Bloom – **The Ehlers-Danlos Society**
Andrea Brown – **National Kidney Federation**
Kripen Dhrona – **British Polio Fellowship**
Sue Dimmock – **UKPIPS**
Brian Gunson – **Liver4Life**
Lesley Kavi – **PoTS UK**

2. MINUTES FROM THE LAST MEETING

Reported: The minutes of the last quarterly meeting on Thursday 19 June 2025 were agreed and will be published on the SHCA website. **Done**

3. MATTERS ARISING

Reported: As per notes on agenda.

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.

4.3 UK Rare Diseases Framework

Reported: As per notes on agenda.

Agreed: Upon request, SHCA Secretariat to circulate the NHS Health Inequalities Toolkit to members. **As appropriate**

5. KEY ACTIVITY

5.1 Mental health stories

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to engage with members as part of 2026 activity on the impact of increases to national insurance contributions on SHCA members' ability to maintain their own mental health support services. **As appropriate**

5.2 Collaboration with Genetic Alliance

Reported: As per notes on agenda.

5.3 Shaping the future of specialised commissioning

Reported: As per notes on agenda.

5.4 NICE patient involvement

Reported: As per notes on agenda.

6. 2026 PLANS

6.1 Annual membership survey

Reported: As per notes on agenda.

6.2 Proposed objectives for 2026

Reported: As per notes on agenda.

6.3 Proposed activities

Agreed: Members approved the following plans for 2026:

- Making rare matter campaign
- Are you okay? amplification and advocacy
- Deciphering delegation
- Vision for the future of specialised commissioning
- Newborn screening briefing series
- Targeted engagement on access reform
- Making the NHS Bill work for rare diseases

7. APPROVAL OF 2026 PLANS AND SECRETARIAT

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

Agreed: Members approved the proposed 2026 plans. **All to note.**

8. GUEST SPEAKERS

Ashley Dalton MP, Minister for Public Health and Prevention (who has responsibility for rare diseases), John Stewart, National Director of Specialised Commissioning, and Ailsa Willens, Head of Highly Specialised Services, at NHS England spoke at the meeting.

9. 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.