

MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE

THURSDAY 16 APRIL 2026 (11:00-13:00)

**THE ARCHBISHOP'S ROOM, MILLBANK HOUSE, LITTLE COLLEGE STREET,
LONDON, SW1A 3SH, AND VIA MICROSOFT TEAMS**

MEETING MINUTES

Present in person:

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

Iain Armstrong – **Pulmonary Hypertension Association UK (PHA UK)**
George Atwell – **Spinal Injuries Association**
Shelley Betts – **Sobi**
Ellie Kirkland – **Muscular Dystrophy UK (MDUK)**
Hilary Longhurst – **DC Action**
Fiona Loud – **Kidney Care UK**
Patricia Osborne – **Brittle Bone Society**

Secretariat:

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

Present via Teams:

Liz Barnard – **Kidney Research UK**
Sam Briggs – **Alexion**
Georgina Carr – **The Neurological Alliance**
Emily Clarke – **Gene People**
Kripen Dhrona – **The British Polio Fellowship**
Louise Farmer – **Sobi**
Lee-Ann Farrell – **J&J Innovative Medicine**
Anna Featherstone – **MPS Society**
Will Highfield – **Vertex**
Louise Jha – **CSL Behring**
Kate Little – **The Haemophilia Society**
Amy Mitchell – **WellChild**
Debra Morgan – **The Haemophilia Society**
Jane Paxton – **DC Action**
Aidan Rylatt – **Sickle Cell Society**
Cristina Sarb – **Novartis**

Victoria Solovieva – **PNH Support**
Chris Sotirelis – **UK Thalassaemia Society**
Diane Splevings – **Takeda**
Pooja Takhar – **Tuberous Sclerosis Association**
Mads Thomsen – **Sanofi**
Cathy Thompson – **Addison’s Disease Self-Help Group (ADSHG)**
Paul Twentyman – **Children’s Heart Foundation**
Lucy Vasiliou – **National Kidney Federation**
Catherine Wallis – **MS Society**
Susan Walsh – **Immunodeficiency UK**
Elise Wilby – **Metabolic Support UK**

1. APOLOGIES

Baroness Keeley – **SHCA, Vice Chair**
Andrea Brown – **National Kidney Federation**
Harriet Holme – **PCD Research**

2. MINUTES FROM THE LAST MEETING

Reported: The minutes of the last quarterly meeting on Thursday 5 February 2026 were agreed and will be published on the SHCA website. **Done**

3. KEY POLICY ISSUES

3.1 Health legislation update

Reported: as per notes on agenda.

3.2 Specialised commissioning reform

Reported: as per notes on agenda.

3.3 Access to rare disease medicines

Reported: as per notes on agenda.

3.4 UK Rare Diseases Framework

Reported: as per notes on agenda.

Agreed: Secretariat to follow-up with Minister with responsibility for rare diseases, Sharon Hodgson MP, on a commitment for a joint meeting with the Neurological Alliance and Genetic Alliance, and to attend a future SHCA quarterly meeting. **Ongoing**

4. KEY ACTIVITY

4.1 Deciphering delegation

Reported: as per notes on agenda.

Agreed: Secretariat to engage with parliamentarians using the 'Introduction to specialised services' briefing in the coming months. **As appropriate**

4.2 Making rare matter campaign

Reported: as per notes on agenda.

Agreed: Members to complete Genetic Alliance's 'Future for Rare' survey. **4 May 2026**

4.3 Newborn screening

Reported: as per notes on agenda.

Agreed: Members to contact the Secretariat team if they would like to be involved in the newborn screening working group activity. **April 2026**

4.4 Mental health advocacy

Reported: as per notes on agenda.

5. GUEST SPEAKERS

John Stewart (National Director of Specialised Commissioning) and Ailsa Willens (Deputy Director of Highly Specialised Services) at NHS England spoke at the meeting.

6. ANY OTHER BUSINESS

Nine 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.