

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE
THURSDAY 5 FEBRUARY 2026 (11:00-13:00)
THE ARCHBISHOP'S ROOM, MILLBANK HOUSE, LONDON, SW1P 3JU, AND
VIA MICROSOFT TEAMS**

MEETING MINUTES

Present in person:

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

Karen Harrison – **Alex TLC**
Georgina Morton – **ArchAngel MLD Trust**
Lachlan Bruce – **CLAPA**
Joe Sousek – **Haemophilia Society**
Joella Melville – **Niemann-Pick UK**
Ian Armstrong – **Pulmonary Hypertension Association**
Louise Farmer – **Sobi UK & Ireland**
Will Highfield – **Vertex Pharmaceuticals**

Secretariat:

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

Present via Teams:

Lisa Murray – **Action for Pulmonary Fibrosis**
Nadira Bullock – **Alexion**
Natalie Tuzcuoglu – **Amicus**
Pat Roberts – **ArchAngel MLD Trust**
Maya Parkin – **Bliss**
Katie Begg – **Blood Cancer Alliance**
Silvia Kraft – **Bone Cancer Research Trust**
Rajwant Kaur Singh – **Children's Heart Federation**
Jane Paxton – **DC Action**
Samantha Barber – **Gene People**
Susan Walsh – **Immunodeficiency UK**
Samantha Sharp – **Kidney Care UK**
Liz Barnard – **Kidney Research UK**
Elise Wilby – **Metabolic Support UK**

Jonathan Gibson – **Metabolic Support UK**
Stella McKernan – **MND Association**
Alison Wilson – **MPS Society**
Charlotte Roy – **Muscular Dystrophy UK**
Andrea Brown – **National Kidney Federation**
Lucy Vasiliou – **National Kidney Federation**
Markus Bell – **Nerve Tumours UK**
Louisa Dallas – **Novartis**
Carolyn Wheatley – **Patients on Intravenous & Nasogastric Nutrition Therapy**
Victoria Solovieva – **PNH Support**
Michelle Kukielka – **Roald Dahl's Marvellous Children's Charity**
Kate Steele – **SHINE**
Aidan Rylatt – **Sickle Cell Society**
Diane Splevings – **Takeda**
Ben Ellmer-Dellow – **Together for Short Lives**
Pooja Takhar – **The Tuberous Sclerosis Association**
Chris Sotirelis – **UK Thalassaemia Society**

1. APOLOGIES

- Laura Clark – **Amicus**
- Debra Morgan – **The Haemophilia Society**
- Steven McIntosh – **Macmillan Cancer Support**
- Catherine Hodder – **Young Epilepsy**

2. MINUTES FROM THE LAST MEETING

Reported: The minutes of the last quarterly meeting on Thursday 23 October 2025 were agreed and will be published on the SHCA website. **Done**

3. MATTERS ARISING

3.1 Corporate supporter update

Reported: As per notes on the agenda.

4. KEY POLICY ISSUES

4.1 NHS reorganisation update

Reported: As per notes on the agenda.

4.2 Specialised commissioning reform

Reported: As per notes on the agenda.

Agreed: Secretariat to continue engaging with NHS England (NHSE) and the Department of Health and Social Care (DHSC) regarding timelines for the publication of its Review of Direct Commissioning functions, the future of what clinical leadership infrastructure will look like and improving transparency of data, in particular publishing Quality Dashboards.
Ongoing

4.3 NICE and CPAG updates

Reported: As per notes on the agenda.

4.4 UK Rare Diseases Framework

Reported: As per notes on the agenda.

Agreed: Secretariat to provide written updates to members following the publication of the 2026 England Rare Disease Action Plan and the devolved nations' progress reports. **As appropriate**

5. KEY ACTIVITY

5.1 NICE valuing rarity report

Reported: As per notes on the agenda.

5.2 Making the NHS Bill work for rare diseases

Reported: As per notes on the agenda.

Agreed: Secretariat to develop an SHCA position paper setting out asks for the NHS Bill.

April 2026

5.3 Deciphering delegation

Reported: As per notes on the agenda.

Agreed: SHCA to circulate an updated draft guide to specialised commissioning for members. **April 2026**

5.4 Shaping the future of specialised commissioning

Reported: As per notes on the agenda.

Agreed: Secretariat to develop a two-page, visually engaging approach for MPs and Peers to introduce them to the delegation of specialised commissioning and support targeted engagement on the NHS Bill. **April 2026**

Agreed: Secretariat to work with the Genetic Alliance UK (GAUK) and the Neurological Alliance to update its position statement following the publication of NHSE's review of direct commissioning functions. **As appropriate**

5.5 Mental health campaign

Reported: As per notes on the agenda.

Agreed: Secretariat to invite SHCA members to participate in support of a Freedom of Information (FOI) request exercise focused on the provision of mental health support for people living with rare conditions, which will then inform a short briefing detailing the scale and impact of the issue for use with parliamentarians. **As appropriate**

5.6 Making rare matter campaign

Reported: As per notes on the agenda.

Agreed: Secretariat to consider engagement with devolved nations policymakers following the Scottish and Welsh parliamentary elections in May to urge commitment on refreshing

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the UK Rare Diseases Framework. **May 2025**

5.7 Targeted engagement on access reform

Reported: As per notes on the agenda.

Agreed: Secretariat to update the SHCA position statement on MHRA reform once the MHRA consultation is published. **As appropriate**

6. GUEST SPEAKER

Dr Graham Shortland, Vice Chair of the UK National Screening Committee (UK NSC), spoke at the meeting.

7. 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.