

MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE

TUESDAY 16 JUNE 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**
Sam Briggs – **Alexion**
Joella Melville – **Niemann-Pick UK (NPUK)**
Samantha Sharp – **Kidney Care UK**

Secretariat:

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

Present via MS Teams:

Liz Barnard – **Kidney Research UK**
Alice Billin – **Cystic Fibrosis Trust**
Georgina Carr – **The Neurological Alliance**
Will Highfield – **Vertex Pharmaceuticals**
Louise Jha – **CSL Vifor**
Rajwant Kaur Singh – **Children's Heart Foundation**
Michelle Kukielka – **Roald Dahl's Marvellous Children's Charity**
Kate Little – **The Haemophilia Society**
Amy Mitchell – **WellChild**
Jane Paxton – **DC Action**
Pat Roberts – **ArchAngel MLD Trust**
Aidan Rylatt – **Sickle Cell Society**
Victoria Solovieva – **PNH Support**
Pooja Takhar – **Tuberous Sclerosis Association**
Sophie Thomas – **MPS Society**
Cathy Thompson – **Addison's Disease Self Help Group**
Natalie Tuzcuoglu – **Amicus Therapeutics**
Lucy Vasiliou – **National Kidney Federation**
Elise Wilby – **Metabolic Support UK**

1. APOLOGIES

- Baroness Keeley – **SHCA, Vice Chair**
- Kripen Dhrona – **British Polio Fellowship**

2. MINUTES FROM THE LAST MEETING

Reported: The minutes of the last quarterly meeting on Thursday 16 April 2026 were agreed and will be published on the SHCA website. **Done**

3. KEY POLICY ISSUES

3.1 Ministerial update

Reported: as per notes on agenda, and it was noted that Preet Gill MP now has responsibility for rare diseases as Parliamentary Under-Secretary of State for Health Innovation and Safety.

Agreed: Secretariat to write a letter to Preet Gill MP's office to invite her to a future SHCA quarterly meeting. **June**

3.2 Health legislation update

Reported: as per notes on agenda.

3.3 Specialised commissioning reform

Reported: as per notes on agenda.

Agreed: Secretariat to seek opportunities for SHCA members to hear from OPIC leads later in the year. **As appropriate**

3.4 DHSC Target Operating Model

Reported: as per notes on agenda.

Agreed: Secretariat to seek clarity on future specialised commissioning structures in the new DHSC and share further information with members. **As appropriate**

3.5 Access to rare disease medicines

Reported: as per notes on agenda.

Agreed: Secretariat to submit a response to the MHRA consultation on a draft rare disease therapies regulatory framework, with members to feed in to the draft submission. **30 July 2026**

3.6 UK Rare Diseases Framework

Reported: as per notes on agenda.

Agreed: Secretariat to write to the new health Ministers in the devolved nations as part of our campaign calling for a renewed, refreshed and recharged UK Rare Diseases Framework. **July**

4. KEY ACTIVITY

4.1 Shaping the future of specialised commissioning

Reported: as per notes on agenda.

Agreed: Secretariat to review and refresh our position statement with The Neurological Alliance and Genetic Alliance UK on the future of specialised commissioning. **Ongoing**

Agreed: Secretariat to analyse the results of the joint survey with the Federation of Specialist Hospitals (FoSH), the Shelford Group and NHS Alliance on how well specialised commissioning is currently working, to inform future engagement with DHSC, NHSE and other national stakeholders. **Ongoing**

4.2 Legislative engagement

Reported: as per notes on agenda.

Agreed: SHCA to share draft submission to the Public Bill Committee for members to feedback on. **Done**

Agreed: Members with specific concerns regarding the Health Bill to get in touch with the secretariat team to help shape our thinking on future engagement with the Bill. **Ongoing**

4.3 Mental health FOI exercise

Reported: as per notes on agenda.

Agreed: Secretariat to analyse results of FOI exercise and draft a new briefing for engagement with MPs and officials highlighting our asks on mental health support for people living with rare conditions. **Ongoing**

Agreed: Secretariat to respond to the consultation on a new Mental Health Strategy, with members to feed in where appropriate. **10 July 2026**

4.4 Making rare matter campaign

Reported: as per notes on agenda.

4.5 Newborn screening advocacy

Reported: as per notes on agenda.

Agreed: Members to engage with the secretariat on the draft position papers on newborn screening. **As appropriate**

5. GUEST SPEAKER

Jason Yiannikou, Director & Chief Operating Officer – Legislation, at the Department of Health and Social Care, 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.