

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE
THURSDAY, 16 JANUARY 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**
Baroness Sater – **Vice Chair, SHCA**

Iain Armstrong – **Pulmonary Hypertension Association UK**
Markus Bell – **Nerve Tumours UK**
Andrew Brown – **Alexion**
Kripen Dhrona – **British Polio Fellowship**
Madhu Haval – **Muscular Dystrophy UK**
Ben Leach – **Amicus Therapeutics**
Joe Smale – **Cystic Fibrosis Trust**
Bob Stevens – **MPS Society**
Portia Thorman – **Spinal Muscular Atrophy UK**

Secretariat:

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

Present via Zoom:

Ailsa Arthur – **Association for Glycogen Storage Disease**
Samantha Barber – **Gene People**
Andrea Brown – **National Kidney Federation**
Lachlan Bruce – **CLAPA**
Emma Cooper – **The Pituitary Foundation**
Ben Dellow – **Together for Short Lives**
Lee-Ann Farrel – **J&J Innovative Medicine**
Jonathan Gibson – **Metabolic Support UK**
Brian Gunson – **Liver4Life**
Jill Harkin – **Sanofi**
Andrew Hollingsworth – **Vertex**
Michelle Kukielka – **Roald Dahl's Marvellous Children's Charity**
Carol Levin – **British Polio Fellowship**
Fiona Loud – **Kidney Care UK**

Rachel Miller-Stainsby – **Myrovlytis Trust**
Patricia Osborne – **Brittle Bone Society**
Maya Parkin – **Bliss**
Lewis Petty – **Spinal Injuries Association**
Alison Railton – **Kidney Research UK**
Pooja Takhar – **Tuberous Sclerosis Association**
Gabriel Theophanous – **UK Thalassaemia Society**
Susan Walsh – **Immunodeficiency UK**
Hannah Winter – **Ipsen**
Len Woodward – **aHUS Alliance**

1. APOLOGIES

- Jane Paxton – **DC Action**

2. MINUTES FROM THE LAST MEETING

Reported: The minutes of the last quarterly meeting on Tuesday 22 October 2024 were agreed and will be published on the SHCA's website. **Done**

3. MATTERS ARISING

3.1 Vice Chair update

Reported: As per notes on agenda.

4. KEY POLICY ISSUES

4.1 NHS pressures

Reported: As per notes on agenda.

4.2 UK Rare Diseases Framework

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to write a letter from the SHCA Chairs to Minister Andrew Gwynne to highlight delays to newborn screening from the UK National Screening Committee (UK NSC) and invite him to the March SHCA quarterly meeting. **Ongoing**

Agreed: SHCA Secretariat to invite a member of the UK NSC to speak at a future quarterly meeting. **As appropriate**

4.3 NICE updates

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to respond to NICE's consultation on HST routing criteria, capturing feedback from members discussed at the meeting. **Thursday 30 January**

4.4 Specialised commissioning reform

Reported: As per notes on agenda.

5. KEY ACTIVITY

5.1 Delegation listening exercise

Reported: As per notes on agenda.

5.2 Launching the UK rare diseases framework stocktake

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to keep members updated on the details of the roundtable event with Genetic Alliance UK where the findings of the stocktake will be presented. **As appropriate**

5.3 Mental health and rare disease stories

Reported: As per notes on agenda.

Agreed: Members that would like to be involved will contact the SHCA Secretariat via email. **Friday 31 January**

5.4 Engagement toolkit

Reported: As per notes on agenda.

Agreed: Members that would like to be involved will contact the SHCA Secretariat via email. **Friday 31 January**

6. GUEST SPEAKERS

John Stewart, National Director, Specialised Commissioning at NHS England, and Roz Lindridge, Regional Director for Commissioning Integration at NHS (Midlands), both spoke at the meeting.

Agreed: SHCA Secretariat to follow up with John and Roz on actions agreed to during the Q&A and update members with any information received in response. **As appropriate**

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.