

MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE
THURSDAY, 20 MARCH 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 Chisholm – **Vice Chair, SHCA**
Baroness Sater – **Vice Chair, SHCA**

Iain Armstrong – **Pulmonary Hypertension Association UK**
Lachlan Bruce – **Cleft Lip and Palate Association (CLAPA)**
Georgina Carr – **The Neurological Alliance**
Cristina Sarb – **Novartis**

Secretariat:

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

Present via Zoom:

Baroness Keeley – **Vice Chair, SHCA**
Samantha Barber – **Gene People**
Liz Barnard – **Kidney Research UK**
Andrew Brown – **Alexion**
Amy Capper – **Myeloma UK**
Emma Cooper – **The Pituitary Foundation**
Hannah Dwyer – **AKU Society**
Richard Gardner – **J&J Innovative Medicine**
Brian Gunson – **Liver4Life**
Jill Harkin – **Sanofi**
Madhu Haval – **Muscular Dystrophy UK**
Ben Leach – **Amicus Therapeutics**
Joella Melville – **Niemann-Pick UK**
Patricia Osborne – **Brittle Bone Society**
Maya Parkin – **Bliss**
Harry Ridgewell – **Cystic Fibrosis Trust**
Samantha Sharp – **Kidney Care UK**
Susan Walsh – **Immunodeficiency UK**
Hannah Winter – **Ipsen**

1. APOLOGIES

- Rachel Miller-Stainsby – **The Myrovlytis Trust**
- Andrea Brown – **National Kidney Federation**
- Alex Saul – **National Kidney Federation**
- John James – **Sickle Cell Society**
- Andrew Gregory – **Vertex**
- Joe Smale – **Cystic Fibrosis Trust**
- Liz Brownnutt – **Batten Disease Family Association**

2. MINUTES FROM THE LAST MEETING

Reported: The minutes of the last quarterly meeting on Thursday 16 January 2025 were agreed with one update and will be published on the SHCA's website. **Done**

3. MATTERS ARISING

3.1 Chair update

Reported: As per notes on agenda.

4. KEY POLICY ISSUES

4.1 National organisations update

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to seek clarity from the Department of Health and Social Care (DHSC) and NHS England (NHSE) on the impact of ongoing changes for rare diseases and specialised commissioning and update SHCA members. **As appropriate**

Agreed: SHCA Secretariat to seek out engagement opportunities during changes to legislation associated with ongoing national organisation reforms. **As appropriate**

Agreed: SHCA to follow-up on ongoing Ministerial engagement given recently announced changes to national organisations. **ASAP**

4.2 UK Rare Diseases Framework

Reported: As per notes on agenda.

Agreed: SHCA to write to each of the devolved nations to request updates on progress made with previous commitments and future action plans. **April**

4.3 NICE highly specialised technologies criteria

Reported: As per notes on agenda.

4.4 Specialised commissioning reform

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to continue communications to members around ongoing changes to specialised commissioning. **As appropriate**

5. KEY ACTIVITY

5.1 Engagement toolkit

Reported: As per notes on agenda.

Agreed: SHCA members to share insights on engagement with ICBs, NHSE or NHS regions to feed into the ICS engagement toolkit. **As appropriate**

5.2 Launching the UK rare diseases framework stocktake

Reported: As per notes on agenda.

5.3 Mental health stories

Reported: As per notes on agenda.

Agreed: SHCA members to continue to reach out to the SHCA Secretariat if they would like to be involved in the project, including by sharing relevant case studies. **Ongoing**

5.4 Transparency of data

Reported: As per notes on agenda.

6. GUEST SPEAKERS

Edward Jones (Assistant Director, Policy) and Georgia Fredriksson (Delivery Manager, Integration) at NHS Confederation both spoke at the meeting.

7. 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.