

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE
THURSDAY 19 JANUARY 2023 (12:00-14:00) VIA ZOOM**

Present:

Lord Sharkey - **Chair, SHCA**
Baroness Chisholm - **Vice Chair, SHCA**
Baroness Wheeler - **Vice Chair, SHCA**

Angela Magny - **Alexion**
Ben Leach - **Amicus Therapeutics**
Chris Wingrove - **Amicus Therapeutics**
Patricia Osborne - **Brittle Bone Society**
Andrea Sharples - **Communication Matters**
Jamie Inkles - **Cystic Fibrosis Trust**
Peter Shand - **Gilead**
Lucy Hescott - **Janssen UK**
Thomas Thorp - **Janssen UK**
Samantha Sharp - **Kidney Care UK**
Ella Guthrie - **Leukaemia Care**
Brian Gunson - **Liver4life**
Tara Steeds - **Lymphoma Action**
Andrea Brown - **National Kidney Federation**
Hannah Verghese - **Neurological Alliance**
Seyi Afolabi - **Sickle Cell Society**
Diane Splevings - **Takeda**
Sarah Berry - **The British Society for Rheumatology**
Sonia Allen - **The Children's Trust**
Ren Renwick - **The Pituitary Foundation**
Andrew Stockley - **PNH Support**
Dr Pooja Takhar - **Tuberous Sclerosis Association**
Andrew Hollingsworth - **Vertex**
Charlotte Roberts - **Vertex**

Secretariat:

Claire Hastings - **SHCA Secretariat**
Ed McIntosh - **SHCA Secretariat**
Henry Poust - **SHCA Secretariat**
Amelia Sunkaraneni - **SHCA Secretariat**

1. GUEST SPEAKER

Reported: A pre-recorded video from Helen Whately MP, Minister of State in the Department of Health and Social Care, was shared at the meeting.

Agreed: SHCA members to share questions they would like included in the letter Lord Sharkey will send to the Minister following the meeting. **27.01.23**

2. APOLOGIES

- Fenella Lloyd - **SHCA Secretariat**
- Samantha Barber - **Gene People**

3. MINUTES FROM THE LAST MEETING

Reported: The minutes of the last meeting on Thursday 6 October 2022 were agreed and will be published on the SHCA's website. **Done**

4. MATTERS ARISING

4.1 SHCA Secretariat update

Reported: Since the last quarterly meeting, Bill Morgan has left the Secretariat to take up the role of Health Policy Adviser to the Prime Minister.

5. KEY POLICY ISSUES

5.1 NHS pressures

Reported: As per notes on agenda.

5.2 UK Rare Diseases Framework

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to share further information on the Department of Health and Social Care's Independent Advisory Groups with interested members. **Done**

Agreed: SHCA Secretariat to circulate a summary of England's 2023 Rare Diseases Action Plan with SHCA members once it is published. **28.02.23**

5.3 Specialised commissioning reform

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to write to SHCA members to share a further update on specialised commissioning reform following NHS England's public board meeting on 2 February. **03.02.23**

6. KEY ACTIVITY

6.1 Assessing access to rare disease treatments

Reported: As per notes on agenda.

6.2 Scrutinising future commissioning

Reported: As per notes on agenda.

6.3 Highlighting delays in diagnosis

Reported: As per notes on agenda.

Agreed: Interested members to contact the SHCA Secretariat if they would like to be involved in the report highlighting delays in diagnosis, including through sharing relevant case studies that could be included in the report. **Ongoing**

Agreed: SHCA Secretariat to set up meetings with individual members interested in being involved in the development of the report. **As appropriate**

6.4 Measuring the impact of the NICE review

Reported: As per notes on agenda.

6.5 Exploring health inequalities in rare diseases

Reported: As per notes on agenda.

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.