

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE
TUESDAY 6 FEBRUARY 2024 (13:00-15:00)
THE ARCHBISHOPS ROOM, MILLBANK HOUSE, LITTLE COLLEGE STREET,
LONDON, SW1P 3SH; AND VIA ZOOM**

Present in person:

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

Markus Bell – **Nerve Tumours UK**
Elliot Bidgood – **Hepatitis C Trust**
Kripen Dhrona – **British Polio Fellowship**
Tony Griffiths – **St Andrew's Healthcare**
Carol Levin – **British Polio Fellowship**
Cristina Sarb – **Novartis**
Peter Shand – **Gilead Sciences**
Joe Smale – **Cystic Fibrosis Trust**

Secretariat:

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

Present via Zoom:

Ailsa Arthur – **Association for Glycogen Storage Disease**
Samantha Barber – **Gene People**
Dan Betts – **CSL Behring**
Andrea Brown – **National Kidney Federation**
Liz Brownnutt – **Batten Disease Family Association**
Amy Capper – **Myeloma UK**
Rich Collins – **GAIN Charity**
Anna Coupland – **RAIRDA**
Ellie Davies – **Cystic Fibrosis Trust**
Ellie Dawes – **The Aplastic Anaemia Trust**
Nicky Fawcett – **CLAPA**
Lesley Harrison – **The Alkaptonuria Society**
Andrew Hollingsworth – **Vertex**
Angela Horsley – **Roald Dahl's Marvellous Children's Charity**
Jessica Jones – **MND Association**
Farhan Khan – **MDUK**
Alice Knapton – **Sarcoma UK**

Michelle Kukielka - **Roald Dahl's Marvellous Children's Charity**
Ben Leach – **Amicus Therapeutics**
Ruth MacLeod – **MS Society**
Joelle Melville – **Niemann-Pick UK**
Rachel Miller-Stainsby – **Myrovlytis Trust**
Lisa Murray – **APF**
Maya Parkin – **Bliss**
Jane Paxton – **DCAction**
Samantha Sharp – **Kidney Care UK**
Rebecca Sheppard – **Children's Heart Foundation**
Pooja Takhar – **Tuberous Sclerosis Association**
Thomas Thorp – **Janssen**
Stevie Tyler – **The Aplasmatic Anaemia Trust**
Mike Wharmby – **Alexion**
Michelle Wilkins – **Children's Liver Disease Foundation**
Sophie Wintrich – **PNH Support**

1. GUEST SPEAKER

Lord Nick Markham, Minister for the Lords at the Department of Health and Social Care (DHSC), and Katherine Bainbridge (Head of Rare Diseases and Emerging Therapies at DHSC) spoke at the meeting.

2. APOLOGIES

- Amy Mitchell – WellChild

3. MINUTES FROM THE LAST MEETING

Reported: The minutes of the last meeting on Thursday 19 October 2023 were agreed and will be published on the SHCA's website. **Done**

4. MATTERS ARISING

4.1 SHCA corporate supporters update

Reported: Since the last quarterly meeting, Ipsen have joined the SHCA as corporate supporters in 2024.

5. KEY POLICY ISSUES

5.1 NHS pressures

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to provide an update upon the publication of NHS England's (NHSE) planning guidance for 2024/25. **As appropriate**

5.2 UK Rare Diseases Framework

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to provide relevant updates on the 2024 Action Plan for England following its publication on Rare Disease Day (29 February 2024). **As appropriate**

5.3 Specialised commissioning reform

Reported: As per notes on agenda.

Agreed: Members agreed that having an Integrated Care Board (ICB) leader from the East of England region attend an SHCA meeting to discuss delegation arrangements in practice would be beneficial. **All to note**

Agreed: Members to share insights with SHCA Secretariat from their work with ICBs post-delegation, including what is working well and any concerns they have. **As appropriate**

5.4 NICE work on rare diseases principles

Reported: As per notes on agenda.

Agreed: SHCA Secretariat encouraged members to feed into consultations on this work. **All to note**

5.5 Voluntary Scheme for Branded Medicines Pricing, Access and Growth (VPAG)

Reported: As per notes on agenda.

6. KEY ACTIVITY

6.1 Scrutinising future commissioning

Reported: As per notes on agenda.

Agreed: Members to share their thoughts on what aspects of the new commissioning arrangements they would like included in the updated guide to specialised commissioning for 2024/25. **As appropriate**

Agreed: Members expressed their interest in hearing insights from different people within ICBs as part of the listening exercise, as well as ensuring it explores a range of rare and complex conditions. **All to note**

6.2 General Election manifesto

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to launch the manifesto around Rare Disease Day 2024. **As appropriate**

6.3 Stocktake on the Rare Disease Framework

Reported: As per notes on agenda.

Agreed: Members to feed into this work at the April quarterly meeting. **All to note**

6.4 Mental health survey

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to launch the survey after the February quarterly meeting. **Done**

Agreed: Members to complete the survey by 27 February 2024. **As appropriate**

6.4 Delays to diagnosis – next steps

Reported: As per notes on agenda.

6.5 Health inequalities – next steps

Reported: As per notes on agenda.

Agreed: Members to get in touch with the SHCA Secretariat if there are any issues included in the report that they particularly want the SHCA to engage with policymakers on. **As appropriate**

6.6 Making the case for updates to NICE's methods and processes

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to share a survey to build an evidence base to support this report.
Summer 2024

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.