

MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE
THURSDAY 19 October 2023 (14:00-16:00)
THE ARCHBISHOPS ROOM, MILLBANK HOUSE, LITTLE COLLEGE STREET,
LONDON, SW1P 3SH; AND VIA ZOOM

Present in person:

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

Harveen Ubhi – **Anthony Nolan**
Maya Parkin – **Bliss**
Kripen Dhrona – **British Polio Fellowship**
Joanna Heath – **Children’s Heart Foundation**
Anna Coupland – **RAIRDA**

Secretariat:

Ed McIntosh – **SHCA Secretariat**
Amelia Sunkaraneni – **SHCA Secretariat**
Fenella Lloyd – **SHCA Secretariat**
Rennie Baxter – **SHCA Secretariat**

Present via Zoom:

Bradley Price – **Action for Pulmonary Fibrosis**
Ben Leach – **Amicus Therapeutics**
Ailsa Arthur – **Association for Glycogen Storage Disease UK**
Patricia Osborne – **Brittle Bone Society**
Katharine McIntosh – **Cardiomyopathy UK**
Gillian McCarthy – **CLAPA**
Ellie Davies – **Cystic Fibrosis Trust**
Lily-Rose Sharry – **Dementia UK**
Samantha Barber – **Gene People**
Deborah Flanagan – **Gilead**
Susan Walsh – **Immunodeficiency UK**
Lucy Hescott – **Janssen**
Daniel Huggins – **MDUK**
Citta Widagdo – **MDUK**
Jonathan Gibson – **Metabolic Support UK**
Jessica Jones – **MND Association**
Madeleine Walpert – **MS Society**
Ruth MacLeod – **MS Society**
Andrew Brown – **National Kidney Federation**
Constantinos Skinitis – **Novartis**

Alice Knapton – **Sarcoma UK**
Andrew Hollingsworth – **Vertex**

1. APOLOGIES

- Brian Gunson – **Liver4Life**
- Bob Stevens – **MPS Society**
- Andy Barrick – **MSA Trust**
- Seyi Afolabi – **Sickle Cell Society**
- Amy Mitchell – **WellChild**

2. MINUTES FROM THE LAST MEETING

Reported: The minutes of the last quarterly meeting on Thursday 15 June 2023 were agreed and will be published on the SHCA's website. **Done**

3. KEY POLICY ISSUES

3.1 NHS pressures

Reported: As per notes on agenda.

3.2 UK Rare Diseases Framework

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to recirculate the link for the National Institute for Health and Care Research (NIHR) report on the rare diseases research landscape. **Done**

Agreed: SHCA Secretariat to continue to discuss the implementation and effectiveness of the Innovative Medicines Fund (IMF) with stakeholders including NHS England (NHSE) and the Department of Health and Social Care (DHSC). **Ongoing**

Agreed: SHCA Secretariat to provide relevant updates on 2023 Action Plans for Scotland and Wales, following the UK Rare Disease Forum on 25 October. **As appropriate**

3.3 Specialised commissioning reform

Reported: As per notes on agenda.

Agreed: Members to share insights with SHCA Secretariat if they have been involved in the development of updated service specifications. **As appropriate**

4. KEY ACTIVITY

4.1 Scrutinising future commissioning

Reported: As per notes on agenda.

4.2 Measuring the impact of the NICE review

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to arrange a meeting with Genetic Alliance UK and the National Institute for Health and Care Excellence (NICE) to consider how the recommendations from the SHCA report can be taken forwards. **Ongoing**

4.3 Exploring health inequalities in rare diseases

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to circulate the newly published report, [Rare diseases, common inequalities: bringing rare diseases into the health inequalities agenda](#), with the membership following the meeting. **Done**

Agreed: SHCA Secretariat to engage with NHSE, DHSC and NICE to discuss findings and recommendations in the report. **As appropriate**

4.4 Survey feedback and member priorities

Reported: As per notes on agenda.

5. PLANS FOR 2024

5.1 Proposed objectives and strategy for 2024

Reported: As per notes on agenda.

5.2 Proposed activities

Agreed: Members approved the following plans for 2024:

- Manifesto for people with rare and complex conditions
- Mental health support
- Health inequalities – report into action
- Future commissioning
- Stocktake on the Rare Disease Framework
- Delays to diagnosis
- Making the case for updates to NICE's methods and processes

Agreed: Members to contact SHCA Secretariat to discuss any revisions or additions to the approved plans. **November**

6. APPROVAL OF 2024 PLANS AND SECRETARIAT

Agreed: Members approved the continuation of Evoke Incisive Health as the Secretariat.

To note

7. GUEST SPEAKER

Professor Jonathan Bengier, Chief Medical Officer at the National Institute for Health and Care Excellence (NICE) spoke at the meeting.

Agreed: Professor Bengier noted NICE's desire to meet and discuss the recently published SHCA report on patient involvement in NICE's decision making. SHCA Secretariat to arrange this meeting. **November**

8. 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.