

## **MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE**

**THURSDAY 15 JUNE 2023 (11:00-13:45)**

**COMMITTEE ROOM G, HOUSE OF LORDS, PALACE OF WESTMINSTER, LONDON,  
SW1A 0PW**

### **Present in person:**

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

Bradley Price - **Action for Pulmonary Fibrosis**  
Andrew Brown - **Alexion**  
Chris Wingrove - **Amicus Therapeutics**  
Ailsa Arthur - **Association for Glycogen Storage Disease**  
Maya Parkin - **Bliss**  
Joanna Heath - **Children's Heart Foundation**  
Harry Ridgewell - **Cystic Fibrosis Trust**  
Samantha Barber - **Gene People**  
Richard Gardner - **Janssen**  
Bob Stevens - **MPS Society**  
Citta Widagdo - **Muscular Dystrophy UK**  
Cassie Staines - **National Kidney Federation**  
Joella Melville - **NPUK**  
Sorrel Bickley - **Sarcoma UK**  
Seyi Afolabi - **Sickle Cell Society**  
Claire Cunniffe - **The Cleft Lip and Palate Association**  
Sam Mountney - **The Neurological Alliance**  
Ren Renwick - **The Pituitary Foundation**  
Pooja Takhar - **Tuberculosis Sclerosis Association**

### **Secretariat:**

Ed McIntosh - **SHCA Secretariat**  
Amelia Sunkaraneni - **SHCA Secretariat**  
Henry Poust - **SHCA Secretariat**  
Fenella Lloyd - **SHCA Secretariat**  
Rennie Baxter - **SHCA Secretariat**

### **1. APOLOGIES**

Patricia Osborne – **Brittle Bone Society**  
Katharine McIntosh – **Cardiomyopathy UK**  
Faradane O'Callaghan – **Dementia UK**  
Brian Gunson – **Liver4Life**  
Jonathan Gibson – **Metabolic Support UK**

Andy Barrick – **MSA Trust**  
Ruth MacLeod – **MS Society**  
Andrea Brown – **National Kidney Foundation**

## **2. MINUTES FROM THE LAST MEETING**

Reported: The minutes of the last quarterly meeting on Thursday 23 March 2023 were agreed and will be published on the SHCA's website. **Done.**

## **3. MATTERS ARISING**

Reported: Reminder of the separate virtual Q+A session with John Stewart, Director of Specialised Commissioning at NHS England (NHSE) and Lauren Hughes, Director for Strategy, Transformation and Quality – Specialised Commissioning at NHSE, on Wednesday 21 June from 14:00 – 15:00.

Agreed: SHCA Secretariat to circulate Zoom details following the quarterly meeting. **Done.**

## **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 draft a letter to the Minister, on behalf of the SHCA membership, to highlight member concerns in relation to the implementation of the UK Rare Diseases Framework. **Following the Q+A session on 21 June.**

Agreed: SHCA Secretariat to consider arranging a meeting between the SHCA Chairs and Vice Chairs and the Department of Health and Social Care (DHSC) before Parliamentary Summer Recess. **June.**

Agreed: SHCA membership to share any suggestions for written parliamentary questions (WPQs). **As appropriate.**

### **4.3 Specialised commissioning reform**

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to attend the Specialised Services Stakeholder Forum meeting on Thursday 29 June and provide any updates to membership. **June.**

## 5. KEY ACTIVITY

### 5.1 Assessing access to rare disease treatments

Reported: As per notes on agenda.

### 5.2 Scrutinising future commissioning

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to circulate link to the third webinar summary once it has been uploaded to the website. **As appropriate.**

### 5.3 Highlighting delays in diagnosis

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to circulate the report, [Navigating the labyrinth: reducing delays to a rare disease diagnosis](#), following the meeting. **Done.**

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

### 5.4 Measuring the impact of the NICE review

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to share a survey and request for one on one with interviews on the impact of the NICE review with the SHCA membership. **Done.**

### 5.5 Exploring health inequalities in rare diseases

Reported: As per notes on agenda.

Agreed: SHCA membership to contact Rennie Baxter (SHCA Secretariat, [rennie.baxter@incisivehealth.com](mailto:rennie.baxter@incisivehealth.com)) if they are interested in contributing to this report. **As appropriate.**

## 6. GUEST SPEAKER

Reported: Richard Douglas, Chair of South East London Integrated Care System (ICS), spoke at the meeting.

## 7. LUNCH AND BRAINSTORM SESSION

Reported: In preparation for the virtual Q+A session with John Stewart and Lauren Hughes on 21 June, members discussed questions they would like to ask NHSE.

Agreed: Members to share any further questions for NHSE with SHCA Secretariat prior to the Q+A session. **20 June.**

## **8. ANY OTHER BUSINESS**

Agreed: It was agreed that an in-person/online hybrid style meeting for future quarterly meetings would be more beneficial for the SHCA membership. **All to note.**

*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.*