

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE**  
**THURSDAY 23 MARCH 2023 (11:00-13:00)**  
**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 Wheeler - **Vice Chair, SHCA**

Ben Leach - **Amicus Therapeutics UK**

Yasmin Sheikh - **Anthony Nolan**

Amelia Holt - **Beat**

Kripen Dhrona - **British Polio Fellowship**

Joanna Heath - **Children's Heart Federation**

Ellie Davis - **Cystic Fibrosis Trust**

Faradane O'Callaghan - **Dementia UK**

Aiden Rylatt - **Hepatitis C Trust**

Matthew Rose - **Muscular Dystrophy UK**

Amanda Mortensen - **The Batten Disease Family Association**

Jeff Courtney - **The Haemophilia Society**

Ren Renwick - **The Pituitary Foundation**

Pooja Takhar - **Tuberous Sclerosis Association**

Amy Mitchell - **WellChild**

**Secretariat:**

Ed McIntosh - **SHCA Secretariat**

Henry Poust - **SHCA Secretariat**

Fenella Lloyd - **SHCA Secretariat**

Rennie Baxter - **SHCA Secretariat**

**Present via Zoom:**

Amelia Sunkaraneni - **SHCA Secretariat**

Chris Wingrove - **Amicus Therapeutics UK**

Beth McCleverty - **Bliss**

Patricia Osborne - **Brittle Bone Society**

Rebecca Cooper - **Children's Liver Disease Foundation**

Peter Shand - **Gilead**

Richard Gardner - **Janssen UK**

Tara Steeds - **Lymphoma Action**

Ruth MacLeod - **MS Society**

Fay Yorath - **Muscular Dystrophy UK**

Adam Freedman - **National AIDS Trust**

Andrea Brown - **National Kidney Foundation**  
Sam Mountney - **National Voices**  
Constantinos Skinitis - **Novartis**  
John James - **Sickle Cell Society**  
Katie Greig - **Teenage Cancer Trust**  
Andrew Hollingsworth - **Vertex**

## **1. GUEST SPEAKER**

Reported: Wes Streeting MP, Shadow Secretary of State for Health and Social Care, spoke at the meeting.

## **2. APOLOGIES**

- Baroness Sater - **Vice Chair, SHCA**
- Andy Barrick - **MSA Trust**

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

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

## **4. MATTERS ARISING**

### **4.1 SHCA Vice-Chair update**

The membership has approved Baroness Sater to join the SHCA as a Vice-Chair and Baroness Chisholm to remain a Vice-Chair, following her appointment as a cross-bench Peer.

### **4.2 SHCA Secretariat update**

Since the last quarterly meeting, Rennie Baxter has joined the SHCA Secretariat and Claire Hastings has left.

## **5. KEY POLICY ISSUES**

### **5.1 NHS pressures**

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to share the start date of the Spring COVID-19 booster programme once confirmed by NHS England (NHSE). **As appropriate.**

### **5.2 Specialised commissioning reform**

Reported: As per notes on agenda.

### **5.3 UK Rare Diseases Framework**

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to continue to share members' concerns and questions with both NHSE and the Department for Health and Social Care, particularly regarding the Innovative Medicines Fund (IMF). **Ongoing.**

#### **5.4 Research and access policy developments**

Reported: As per notes on agenda.

### **6. KEY ACTIVITY**

#### **6.1 Assessing access to rare disease treatments**

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to circulate a survey amongst the membership (in conjunction with activity 6.4) about access to medicines and the success of the IMF. **June**

#### **6.2 Scrutinising future commissioning**

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to circulate the link to the specialised commissioning explainer now [published](#) on the website, and reshare the invitation to the SHCA's equitable access to high-quality specialised services webinar on 27 March. **Done**

#### **6.3 Highlighting delays in diagnosis**

Reported: As per notes on agenda.

Agreed: Members to share short quotes with SHCA Secretariat on the impact of delays to rare disease diagnosis on patients and their families to be cited in the report. **Ongoing**

#### **6.4 Measuring the impact of the NICE review**

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to circulate a survey amongst the membership (in conjunction with activity 6.1) and arrange interviews about access to medicines and members' experiences with NICE processes. **June**

#### **6.5 Exploring health inequalities in rare diseases**

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to approach the membership for interviews regarding the impact of

health inequalities on people living with rare and complex conditions. **June**

## **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.*