

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE (SHCA), THURSDAY 6  
OCTOBER 2022 (11:00–13:00) VIA ZOOM**

**Present:**

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

Angela Magny - **Alexion**  
Ben Leach - **Amicus Therapeutics**  
Amanda Mortensen - **Batten Disease Family Association**  
Beth McClevery - **Bliss**  
Sarah Berry - **British Society for Rheumatology**  
Patricia Osborne - **Brittle Bone Society**  
Joanna Heath - **Children's Heart Federation**  
Rebecca Cooper - **Children's Liver Disease Foundation**

**Communication Matters**

Dan Betts - **CSL Behring**  
Jamie Inkles - **Cystic Fibrosis Trust**  
Faradane O'Callaghan - **Dementia UK**  
Samantha Barber - **Gene People**  
Peter Shand - **Gilead**  
Ella Guthrie - **Leukaemia Care**  
Brian Gunson - **Liver4life**  
Johnathan Gibson - **Metabolic Support UK**  
Alex Massey - **Motor Neurone Disease Association**  
Bob Stevens - **MPS Society**  
Michaela Regan - **Muscular Dystrophy UK**  
Matthew Rose - **Muscular Dystrophy UK**  
Cheryl Gowar - **National AIDS Trust**  
Andrea Brown - **National Kidney Federation**  
Joella Metcalfe - **Niemann-Pick UK**  
Mary-Beth Peddell - **Novartis**  
Sam Carney - **Parkinson's UK**  
Susan Passmore - **PWSA UK**  
Bradley Price - **Sarcoma UK**  
Jefferson Courtney - **The Haemophilia Society**  
Ren Renwick - **The Pituitary Foundation**  
Pooja Takhar - **Tuberous Sclerosis Association**  
Andrew Hollingsworth - **Vertex**  
Amy Mitchell - **WellChild**

**Secretariat:**

Claire Hastings - **SHCA Secretariat**  
Fenella Lloyd - **SHCA Secretariat**  
Ed McIntosh - **SHCA Secretariat**  
Bill Morgan - **SHCA Secretariat**

Henry Poust - **SHCA Secretariat**

## **1. GUEST SPEAKER**

Richard Douglas, Chair of South East London Integrated Care System, spoke at the meeting.

## **2. APOLOGIES**

- Baroness Wheeler - **Vice Chair, SHCA**
- Amelia Sunkaraneni - **SHCA Secretariat**
  
- Dave Bracher - **Spinal Injuries Association**
- Sue Dimmock - **UK Primary Immune-deficiency Patient Support**

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

Reported: The minutes of the last meeting on Monday 27 June 2022 were agreed and will be published on the SHCA's website. **Done.**

## **4. MATTERS ARISING**

Reported: Since the last quarterly meeting Addison's Disease Self-Help Group and Myrovlytis Trust have joined the SHCA. **To note.**

## **5. KEY POLICY ISSUES**

### **5.1 New government and health ministers**

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to share an update on Ministerial responsibilities once confirmed.  
**As appropriate.**

### **5.2 NHS recovery and waiting times**

Reported: As per notes on agenda.

### **5.3 COVID recovery and cost of living**

Reported: As per notes on agenda.

### **5.4 Specialised commissioning reform**

Reported: As per notes on agenda.

### **5.5 UK Rare Diseases Framework – implementation plans**

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to provide an update on the Scotland Action Plan once it is published. **As appropriate.**

## **5.6 Innovative Medicines Fund and NICE**

Reported: As per notes on agenda.

## **6. KEY ACTIVITY**

### **6.1 Website update**

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to update the website to include relevant information on social care. **Done.**

### **6.2 Survey feedback and member priorities**

Reported: As per notes on agenda.

## **7. 2023 PLANS**

### **7.1 Proposed objectives and strategy for 2023**

Reported: As per notes on agenda.

### **7.2 Proposed activities**

Agreed: Members approved six proposed plans for 2023:

- Assessing access to rare disease treatments
- Scrutinising future commissioning
- Highlighting delays in diagnosis
- Measuring the impact of the NICE review
- Exploring health inequalities in rare diseases
- Hosting a specialised services summit

## **8. APPROVAL OF 2023 PLANS AND SECRETARIAT**

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

## **9. 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.*