

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE  
TUESDAY, 16 APRIL 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**

Robert Dalglish – **Fanconi Hope**  
Kripen Dhrona – **British Polio Fellowship**  
Vicky Hargreaves – **Novartis**  
Daniel Huggins – **MDUK**  
Fiona Loud – **Kidney Care UK**  
Jerome Penn – **Takeda**  
Joe Smale – **Cystic Fibrosis Trust**  
Bob Stevens – **MPS Society**

**Secretariat:**

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

**Present via Zoom:**

Andrea Brown – **National Kidney Federation**  
Andrew Brown – **Alexion**  
Liz Brownnutt – **Batten Disease Family Association**  
Caroline Chapman – **Brittle Bone Society**  
Deb Flanagan – **Gilead Sciences**  
Andrew Gregory – **Vertex**  
Lucy Hescott – **Janssen**  
Jessica Jones – **MND Association**  
Alice Knapton – **Sarcoma UK**  
Michelle Kukielka - **Roald Dahl's Marvellous Children's Charity**  
Ben Leach – **Amicus Therapeutics**  
Gillian McCarthy – **CLAPA**  
Sarah McPoland – **Communication Matters**  
Joella Melville – **Niemann-Pick UK**  
Maya Parkin – **Bliss**  
Jane Paxton – **DC Action**

**Samantha Sharp – Kidney Care UK**  
**Pooja Takhar – Tuberos Sclerosis Association**

## 1. GUEST SPEAKERS

John Stewart (National Director, Specialised Commissioning) and Lauren Hughes (Director of Strategy, Transformation and Quality, Specialised Commissioning) from NHS England (NHSE) spoke at the meeting.

Agreed: SHCA Secretariat to follow up with NHSE on key points of concern for members discussed at the meeting, and to secure attendance of an Integrated Care Board (ICB) representative for the SHCA's October quarterly meeting. **Ongoing**

## 2. APOLOGIES

- John James – **Sickle Cell Society**
- Samantha Barber – **Gene People**

## 3. MINUTES FROM THE LAST MEETING

Reported: The minutes of the last quarterly meeting on Tuesday 6 February 2024 were agreed and will be published on the SHCA's website. **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 consider engagement with devolved nations to support implementation of the Rare Diseases Framework and publication of respective Rare Disease Action Plans. **As appropriate**

### 4.3 Specialised commissioning reform

Reported: As per notes on agenda.

Agreed: Members to get in touch with **SHCA** Secretariat with their experiences of the new specialised commissioning arrangements as delegation progresses, if they have any concerns. **As appropriate**

Agreed: SHCA Secretariat to circulate relevant NHSE board papers containing the full list of amber 'delegated' services with members who requested it. **Done**

#### **4.4 NICE activity**

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to provide an update on relevant NICE consultations as and when there are announcements. **As appropriate**

### **5. KEY ACTIVITY**

#### **5.1 Manifesto for General Election**

Reported: As per notes on agenda.

Agreed: Members to consider using content from the SHCA and Genetic Alliance's Rare Disease Manifesto for their own advocacy work in the run up to a UK general election in 2024. **All to note**

#### **5.2 Scrutinising future commissioning**

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to update the draft *Guide to specialised commissioning in 2024/25* following the discussion with NHSE and share a final draft version with members before publication. **w/c 22.04.24**

#### **5.3 Mental health survey**

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to upload the briefing to the SHCA website and share with relevant stakeholders at NHSE and DHSC. **Done**

Agreed: Members to consider using survey findings from the briefing in their own advocacy work, and to provide suggestions on how to take this work forward in the future. **As appropriate**

#### **5.4 Stocktake on the Rare Diseases Framework**

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to canvass member opinion on the priorities and effectiveness of the UK Rare Diseases Framework to inform the stocktake. **May 2024**

#### **5.5 Delays to diagnosis**

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to publish an analysis of progress made with diagnosis commitments at the next quarterly meeting. **June 2024**

## **6. 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.*