

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE  
WEDNESDAY, 24 JULY 2024 (12:30-14:30)  
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**

Jefferson Courtney – **The Haemophilia Society**  
Alison Railton – **Kidney Research UK**  
Cristina Sarb – **Novartis**  
Joe Smale – **Cystic Fibrosis Trust**  
Bob Stevens – **MPS Society**  
Hannah Winter – **Ipsen**

**Secretariat:**

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

**Present via Zoom:**

Judy Abel – **British Rheumatology Society**  
Sonia Allen – **The Children's Trust**  
Kielan Arblaster – **MND Association**  
Samantha Barber – **Gene People**  
Markus Bell – **Nerve Tumours UK**  
Jayne Bressington – **PAWS-GIST**  
Andrew Brown – **Alexion**  
Simon Butler – **Sanofi**  
Sarah Dearman – **The Children's Hyperinsulinism Charity**  
Kripen Dhrona – **British Polio Fellowship**  
Jill Harkin – **Sanofi**  
Lucy Hescott – **Janssen**  
Andrew Hollingsworth – **Vertex Pharmaceuticals**  
John James – **Sickle Cell Society**  
Jessica Jones – **National Kidney Federation**  
Ben Leach – **Amicus Therapeutics**  
Toni Mathieson – **Niemann-Pick UK**  
Gillian McCarthy – **CLAPA**  
Katherine McIntosh – **Cardiomyopathy UK**

Rachel Miller-Stainsby – **Myrovlytis Trust**  
Amy Mitchell – **WellChild**  
Patricia Osborne – **Brittle Bone Society**  
Maya Parkin – **Bliss**  
Jane Paxton – **DC Action**  
Peter Shand – **Gilead Sciences**  
Lily-Rose Sharry – **Dementia UK**  
Diane Splevings – **Takeda**  
Pooja Takhar – **Tuberous Sclerosis Association**

## 1. GUEST SPEAKER

Bill Morgan (former Health Adviser in Number 10) spoke at the meeting.

## 2. APOLOGIES

- Andrea Brown – **National Kidney Federation**
- Samantha Sharp – **Kidney Care UK**
- Brian Gunson – **Liver4Life**

## 3. MINUTES FROM THE LAST MEETING

Reported: The minutes of the last quarterly meeting on Tuesday 16 April 2024 were agreed and will be published on the SHCA's website. **Done**

## 4. KEY POLICY ISSUES

### 4.1 General Election

Reported: As per notes on agenda.

Agreed: SHCA Secretariat have a commitment from Ministers Andrew Gwynne MP and Baroness Merron to attend a future SHCA meeting and will look to secure one of them as a speaker for the January 2025 quarterly meeting. **As appropriate**

### 4.2 UK Rare Diseases Framework

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to keep members updated on NICE's severity modifier review and NHSE's health inequalities toolkit. **As appropriate**

Agreed: SHCA Secretariat to raise the issue of time taken for DHSC to name a partner for their research on diagnosis delays. **As appropriate**

### 4.3 Specialised commissioning reform

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to secure an ICB speaker for the October 2024 quarterly meeting. **As appropriate**

## 5. KEY ACTIVITY

### 5.1 Post-Election engagement

Reported: As per notes on agenda.

Agreed: SHCA to write a letter to the new minister with responsibilities for rare diseases, Andrew Gwynne MP, sharing SHCA's manifesto and requesting that the minister speaks at a future quarterly meeting. **August 2024**

### **5.2 Delays to diagnosis – Measuring progress one year on**

Reported: As per notes on agenda.

Agreed: Members to consider sharing the report on social media channels or with other stakeholders for awareness. **As appropriate**

### **5.3 Scrutinising future commissioning**

Reported: As per notes on agenda.

Agreed: Members interested in participating in this listening exercise to get in touch with the SHCA Secretariat. **As appropriate**

### **5.4 Making the case for updates to NICE's methods and processes – survey**

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to share draft report with members for feedback by 9 August. **Done**

Agreed: SHCA Secretariat to finalise report and share with senior stakeholders at NICE, NHSE and DHSC. **As appropriate**

### **5.5 Stocktake on the UK Rare Diseases Framework**

Reported: As per notes on agenda.

## **6. ANY OTHER BUSINESS**

*Eleven 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.*