

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE (SHCA), MONDAY 21  
MARCH 2022 (11:00–13:00) VIA VIDEOCONFERENCE**

**Present:**

Tina Nesbitt - **AGS UK Network**  
Ciarán Scott - **AKU Society**  
Angela Magny - **Alexion**  
Ben Leach - **Amicus Therapeutics**  
Amanda Mortensen - **Batten Disease Family Association**  
Graham Coates - **BioMarin**  
Beth McCleverty - **Bliss**  
Andrea Sharples - **Communication Matters**  
Jamie Inkles - **Cystic Fibrosis Trust**  
Samantha Barber - **Gene People**  
Deborah Flanagan - **Gilead**  
Richard Gardner - **Janssen UK**  
Samantha Sharp - **Kidney Care UK**  
Ella Guthrie - **Leukaemia Care**  
Deborah Bent - **Limbless Association**  
Brian Gunson - **Liver4life**  
Jak Swain - **Metabolic Support UK**  
Bob Stevens - **MPS Society**  
Ruth MacLeod - **MS Society**  
Michaela Regan - **Muscular Dystrophy UK**  
Pete Revell - **National Kidney Federation**  
Sam Mountney - **Neurological Alliance**  
Joella Metcalfe - **Niemann-Pick UK**  
Louise Calland - **Novartis**  
Laura Mullaney - **Parkinson's UK**  
Allan Muir - **Pompe Support Network**  
Susan Passmore - **PWSA UK**  
Seyi Afolabi - **Sickle Cell Society**  
Dave Bracher - **Spinal Injuries Association**  
Portia Thorman - **Spinal Muscular Atrophy UK**  
Diane Splevings - **Takeda**  
Sonia Allen - **The Children's Trust**  
Louise Fish - **Tuberous Sclerosis Association**  
Sue Dimmock - **UK Primary Immune-deficiency Patient Support**  
Roanna Maharaj - **UK Thalassaemia Society**  
Andrew Gregory - **Vertex**

**Secretariat:**

Amelia Chong - **SHCA Secretariat**  
Claire Hastings - **SHCA Secretariat**  
Fenella Lloyd - **SHCA Secretariat**  
Ed McIntosh - **SHCA Secretariat**

Bill Morgan - **SHCA Secretariat**  
Henry Poust - **SHCA Secretariat**

## **1. APOLOGIES**

- Amanda Elliot - **Contact a Family**
- Andy Barrick – **MSA Trust**
- Andrea Brown – **National Kidney Federation**

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

Reported: The minutes of the last meeting on Wednesday 26 January 2022 were agreed and will be published on the SHCA's website. **Done.**

## **3. MATTERS ARISING**

Reported: There were no matters arising.

## **4. KEY POLICY ISSUES**

### **4.1 NHS recovery**

Reported: As per notes on agenda.

### **4.2 COVID recovery**

Reported: As per notes on agenda.

Agreed: The SHCA Secretariat to draft a response to the UK COVID-19 Inquiry. **As appropriate.**

Agreed: The SHCA Secretariat to write to the Secretary of State for Health and Social Care and Baroness Hallett, Chair of the Inquiry, to raise member concerns on its draft terms of reference. **March 2022.**

Agreed: Members to feed in additional concerns they would like raised in the response. **As appropriate.**

### **4.3 Health and Care Bill**

Reported: As per notes on agenda.

### **4.4 Specialised commissioning reform**

Reported: As per notes on agenda.

### **4.5 UK Rare Diseases Framework – England Rare Diseases Action Plan**

Reported: As per notes on agenda.

Agreed: The SHCA Secretariat to keep members updated on the rare disease implementation plans of the devolved nations. **Ongoing.**

Agreed: The SHCA Secretariat to raise member concerns on the lack of focus on coordination of care in its forthcoming meeting with the Department for Health and Social Care's rare diseases team ahead on the Rare Diseases Framework. **April 2022.**

Agreed: Members to feed in any additional suggestions for agenda items they would like the Secretariat to raise in the meeting. **Ongoing.**

#### **4.6 Innovative Medicines Fund**

Reported: As per notes on agenda.

### **5. KEY ACTIVITY**

#### **5.1 Website update**

Reported: As per notes on agenda.

#### **5.2 Quantifying the rare disease backlog**

Reported: As per notes on agenda.

Agreed: The SHCA Secretariat to keep members updated on developments surrounding the quantifying the rare disease backlog campaign. **Ongoing.**

Agreed: Members to share any further suggestions on case studies that could be used as part of the campaign to illustrate the impact of the backlog on people with rare and less common conditions. **Ongoing.**

#### **5.3 Reactivating the NICE Citizen's Council**

Reported: As per notes on agenda.

Agreed: The SHCA Secretariat to circulate minutes from the March NICE public board meeting. **March 2022.**

### **6. GUEST SPEAKER**

The following representatives from NHS England spoke at the meeting: John Stewart, Director, Specialised Commissioning; Lauren Hughes, Director of Strategy, Transformation and Quality, Specialised Commissioning; and Gareth Arthur, Director, NHS England & NHS Improvement.

## **7. ANY OTHER BUSINESS**

Agreed: The SHCA Secretariat to send an email confirming the date of the next Quarterly Meeting. **Done.**

*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.*