

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE (SHCA), WEDNESDAY 26  
JANUARY 2022 (11:00–13:00) VIA VIDEOCONFERENCE**

**Present:**

Tina Nesbitt - **AGS UK network**  
Michael Warne - **AKU Society**  
Sara Hunt - **Alex, The Leukodystrophy Charity**  
Angela Magny - **Alexion**  
Ben Leach - **Amicus Therapeutics**  
Graham Coates - **BioMarin**  
Beth McCleverty - **Bliss**  
Patricia Osborne - **Brittle Bone Society**  
Amanda Batten - **Contact a Family**  
Samantha Barber - **Gene People**  
Deborah Flanagan - **Gilead**  
Richard Gardner - **Janssen UK**  
Megan Fryer-Kelsey - **Metabolic Support UK**  
Ella Guthrie - **Leukaemia Care**  
Deborah Bent - **Limbless Association**  
Jess Doyle - **Metabolic Support UK**  
Bob Stevens - **MPS Society**  
Ruth Macleod - **MS Society**  
Michaela Regan - **Muscular Dystrophy UK**  
Calum Douglas - **National AIDS Trust**  
Hannah Ward - **National AIDS Trust**  
Andrea Brown - **National Kidney Federation**  
Sam Mountney - **Neurological Alliance**  
Joella Metcalfe - **Niemann-Pick UK**  
Vicky Hargreaves - **Novartis**  
Louise Calland - **Novartis**  
Tess Harris - **Polycystic Kidney Disease Charity**  
Allan Muir - **Pompe Support Network**  
Susan Passmore - **PWSA UK**  
Joe Brett - **Silence Therapeutics**  
Portia Thorman - **Spinal Muscular Atrophy UK**  
Sophie Meagher - **Sue Ryder**  
Helen Ross - **Teenage Cancer Trust**  
Sam Williams - **The Aplastic Anaemia Trust**  
Sonia Allen - **The Children's Trust**  
Colin Kerr - **The Children's Trust**  
Jeff Courtney - **The Haemophilia Society**  
Louise Fish - **Tuberous Sclerosis Association**  
Sue Dimmock - **UK Primary Immune-deficiency Patient Support**  
Andrew Gregory - **Vertex**  
Colin Dyer - **WellChild**  
Catherine Hodder - **Young Epilepsy**

## **Secretariat:**

Bill Morgan - **SHCA Secretariat**  
Claire Hastings - **SHCA Secretariat**  
Ed McIntosh - **SHCA Secretariat**  
Amelia Chong - **SHCA Secretariat**  
Henry Poust - **SHCA Secretariat**  
Fenella Lloyd - **SHCA Secretariat**

## **1. APOLOGIES**

- Lord Sharkey - **Chair, SHCA**
- Baroness Wheeler - **Vice Chair, SHCA**
- John James - **Sickle Cell Society**
- Dave Bracher - **Spinal Injuries Association**

Bill Morgan of the SHCA Secretariat chaired the meeting.

## **2. GUEST SPEAKER**

Reported: As per notes on agenda.

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

Reported: The minutes of the last meeting on Wednesday 6 October 2021 were agreed and will be published on the SHCA's website. **Done.**

## **4. MATTERS ARISING**

### **4.1 SHCA corporate supporters update**

Alexion and Silence Therapeutics have joined the SHCA as corporate supporters in 2022. The Secretariat is exploring options for using the additional resource, with an update to the SHCA website identified as a priority.

### **4.2 Secretariat update**

Since the last quarterly meeting, Fenella Lloyd and Amelia Chong have joined the Secretariat.

## **5. KEY POLICY ISSUES**

### **5.1 NHS Recovery**

Reported: As per notes on agenda.

Agreed: Members to share any concerns about the return to Plan A guidance that they would like the SHCA to campaign on. **Ongoing.**

## **5.2 Health and Care Bill / Integrated Care Systems**

Reported: As per notes on agenda.

## **5.3 UK Rare Diseases Framework – national action plans**

Reported: As per notes on agenda.

## **5.4 NICE reform/Innovative Medicines Fund**

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to raise member concerns relating to high-cost drugs in the national tariff with NHS England. **Ongoing.**

Agreed: SHCA Secretariat to capture members' concerns around the proposals for the Innovative Medicines Fund in the SHCA consultation response, including that the scope of the IMF be reserved for those rare disease medicines where speed of access is particularly important. **Done.**

## **6. KEY ACTIVITY**

### **6.1 Health and Care Bill engagement**

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to circulate with members the parliamentary briefing on the Health and Care Bill that has been shared with MPs and Peers as the Bill has progressed through Parliament. **Done.**

Agreed: SHCA Secretariat to continue to support engagement on the Bill, in line with SHCA asks. **Ongoing.**

### **6.2 Quantifying the rare disease backlog**

Reported: As per notes on agenda.

Agreed: Members to share case studies that they would like to be showcased as part of the campaign. **Ongoing.**

Agreed: SHCA Secretariat to keep members updated on the development of the campaign. **Ongoing.**

### **6.3 Involving patients in medicines access reform**

Reported: As per notes on agenda.

### **6.4 Integrated Care Systems – impact on specialised services**

Reported: As per notes on agenda.

### **6.5 Reactivating the NICE Citizens' Council**

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to write to the incoming NICE Chief Executive, Dr Sam Roberts, inviting her to speak at an SHCA quarterly meeting in 2022. **As appropriate.**

### **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.*