

MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE (SHCA), MONDAY 27 JUNE 2022 (11:00–13:00) VIA VIDEOCONFERENCE

Present:

Lord Sharkey - **Chair, SHCA**
Baroness Wheeler – **Vice Chair, SHCA**

Ben Leach - **Amicus Therapeutics**
Amanda Mortensen - **Batten Disease Family Association**
Patricia Osborne - **Brittle Bone Society**
Katherine Myles - **Children's Liver Disease Foundation**
Amanda Elliot - **Contact**
Dan Betts - **CSL Behring**
Jamie Inkles - **Cystic Fibrosis Trust**
Faradane O'Callaghan - **Dementia UK**
Diana Ribeiro - **Janssen UK**
Samantha Sharp - **Kidney Care UK**
Deborah Bent - **Limbless Association**
Jak Swain - **Metabolic Support UK**
Ruth MacLeod - **MS Society**
Michaela Regan - **Muscular Dystrophy UK**
Andrea Brown - **National Kidney Federation**
Constantinos Skinitis – **Novartis**
Maria Piggitt – **PNH Support**
Susan Passmore - **PWSA UK**
Seyi Afolabi - **Sickle Cell Society**
Jeff Courtney - **The Haemophilia Society**
Ren Renwick - **The Pituitary Foundation**
Louise Fish - **Tuberous Sclerosis Association**
Arlene Smyth - **Turner Syndrome Support Society (UK)**
Andrew Hollingsworth - **Vertex**

Secretariat:

Amelia Chong - **SHCA Secretariat**
Claire Hastings - **SHCA Secretariat**
Ed McIntosh - **SHCA Secretariat**
Henry Poust - **SHCA Secretariat**

1. APOLOGIES

- Baroness Chisholm – **Vice Chair, SHCA**
- Sue Dimmock – **UK Primary Immune-deficiency Patient Support**
- Roger Greenwood – **NHS England**
- Brian Gunson – **Liver4Life**
- Fenella Lloyd – **SHCA Secretariat**

2. MINUTES FROM THE LAST MEETING

Reported: The minutes of the last meeting on Monday 21 March 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.

Agreed: The SHCA Chair and Vice Chairs to highlight the need for a public consultation that involves patient groups on the Secretary of State for Health and Social Care's review of workforce planning due in the autumn in parliamentary engagement. **As appropriate.**

4.2 COVID recovery

Reported: As per notes on agenda.

4.3 Specialised commissioning reform

Reported: As per notes on agenda.

Agreed: In its ongoing engagement with NHS England, the SHCA Secretariat to raise members' concerns on:

- The need for additional clarity on timelines for the updates of service specifications that have been identified as a priority for update by NHS England, and whether this will happen prior to delegation of some services in April 2023
- The need for improved accountability of Integrated Care Boards (ICBs) to NHS England of services they commission. **Ongoing**

Agreed: The SHCA Secretariat to continue to share updates with members relating to NHS England's Future Commissioning Models Programme, including the pre-delegation assessment framework. **July 2022**

4.4 UK Rare Diseases Framework – implementation plans

Reported: As per notes on agenda.

4.5 Innovative Medicines Fund

Reported: As per notes on agenda.

5. KEY ACTIVITY

5.1 Website update

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to share a link the the new SHCA website once it has been fully finalised. **July 2022**

5.2 Highlighting the challenges in service recovery for rare diseases

Reported: As per notes on agenda.

Agreed: SHCA members to share any additional case studies that could be used as part of the campaign to highlight the challenges in service recovery for rare diseases. **Ongoing**

Agreed: SHCA Chair and Vice Chairs to highlight case studies on the challenges in service recovery for rare disease patients in parliamentary engagement, including through oral and topical questions as well as written questions. **As appropriate**

5.3 Reactivating the NICE Citizen's Council

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to prepare a short paper making the case for NICE Listens to carry out work on rare diseases, that includes a focus on health inequalities and the under representation of certain groups in research. **July 2022**

6. GUEST SPEAKER

Sheela Upadhyaya, Rare Diseases & RAPID-C19 Strategic Advisor at the National Institute for Health and Care Excellence (NICE), spoke at the meeting.

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.