

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE, WEDNESDAY 6 OCTOBER
2021 (11:00–13:00) VIA VIDEOCONFERENCE**

Present:

Lord Sharkey - **Chair, SHCA**

Tina Nesbitt - **AGS UK network**

Ciarán Scott - **AKU Society**

Sara Hunt - **Alex, The Leukodystrophy Charity**

Kerry Leeson-Beevers - **Alstrom Syndrome UK**

Gerard McCaughey - **Amicus Therapeutics**

Yasmin Sheikh - **Anthony Nolan**

Amanda Mortensen - **Batten Disease Family Association**

Coreen Kelday - **Brittle Bone Society**

Patricia Osborne - **Brittle Bone Society**

Colin Kerr - **The Children's Trust**

Andrea Sharples - **Communication Matters**

Dan Betts - **CSL Behring**

Ben Kind - **Cystic Fibrosis Trust**

Samantha Barber - **Gene People**

Deborah Flanagan – **Gilead**

Jeff Courtney - **The Haemophilia Society**

Susan Walsh - **Immunodeficiency UK**

Richard Gardner - **Janssen UK**

Samantha Sharp - **Kidney Care UK**

Ella Guthrie - **Leukaemia Care**

Deborah Bent - **Limbless Association**

Brian Gunson - **Liver4life**

Jill Praver - **LPLD Alliance**

Jess Doyle - **Metabolic Support UK**

Kirsty Hoyle - **Metabolic Support UK**

Bobby Ancil - **Muscular Dystrophy UK**

Michaela Regan - **Muscular Dystrophy UK**

Cheryl Gowar - **National AIDS Trust**

Andrea Brown - **National Kidney Federation**

Sam Mountney - **Neurological Alliance**

Jackie Imrie - **Niemann-Pick UK**

Louise Calland - **Novartis**

Sam Carney - **Parkinson's UK**

Allan Muir - **Pompe Support Network**

Jo Bullingham - **PoTS UK**

Seyi Afolabi - **Sickle Cell Society**

Diane Splevings - **Takeda**

Louise Fish - **Tuberous Sclerosis Association**

Sue Dimmock - **UK Primary Immune-deficiency Patient Support**

Andrew Gregory - **Vertex**

Catherine Hodder - **Young Epilepsy**

Secretariat:

Bill Morgan - **SHCA Secretariat**
Claire Hastings - **SHCA Secretariat**
Ed McIntosh - **SHCA Secretariat**
Henry Poust - **SHCA Secretariat**
James Maxwell - **SHCA Secretariat**

1. APOLOGIES

- Baroness Wheeler - **Vice Chair, SHCA**
- John James - **Sickle Cell Society**
- Susan Passmore - **PWSA UK**

2. MINUTES

Reported: The minutes of the last meeting on Wednesday 9 June 2021 were agreed and will be published on the SHCA's website. **Done**

3. MATTERS ARISING

Reported: There were no matters arising.

4. SHCA VICE CHAIR UPDATE

Reported: Baroness Chisholm of Owlpen has been temporarily appointed to the Conservative frontbench to cover for a period of parental leave, which conflicts with her role as Vice Chair of the SHCA. Lord Sharkey and Baroness Wheeler have therefore agreed that Baroness Chisholm will temporarily stand down as Vice Chair whilst she fulfils her frontbench duties. No replacement is being sought, and Baroness Chisholm is expected to return as Vice Chair in early 2022.

5. KEY POLICY ISSUES

5.1 Ministerial appointments

Reported: As per notes on agenda.

5.2 NHS recovery

Reported: As per notes on agenda.

5.3 Social care reform

Reported: As per notes on agenda.

5.4 Health and Care Bill/ICs

Reported: As per notes on agenda.

5.5 UK Rare Diseases Framework – national action plans

Reported: As per notes on agenda.

Agreed: The SHCA Secretariat to provide an update on opportunities for engagement with the development of the national action plans of the UK Rare Disease Framework. **29 October 2021.**

5.6 NICE reform/Innovative Medicines Fund

Reported: As per notes on agenda.

Agreed: Members to provide the SHCA Secretariat with feedback on the proposed response to the NICE reform consultation. **11 October 2021.**

Agreed: The SHCA Secretariat to provide an update on opportunities for engagement with the development of the Innovative Medicines Fund, and prepare a response for members' input following the publication of the consultation.

5.7 Devolved nations update

Reported: As per notes on agenda.

6. KEY ACTIVITY

6.1 Specialised services delegation survey and NHS England engagement

Reported: As per notes on agenda.

Reported: Lord Sharkey provided an update on the recent meeting to discuss the findings of the survey on specialised services delegation, including next steps for engagement and the areas of contention: shared feeling of unpreparedness among ICSs and the need for NHS England to provide additional clarity on their proposals including justification.

Agreed: The SHCA Secretariat to provide members with a summary on the survey's findings and next steps. **15 October 2021.**

6.2 Access to medicines review

Reported: As per notes on agenda.

7. 2022 PLANS

7.1 Proposed objectives and strategy for 2022

Reported: the SHCA Secretariat updated members on its plans and objectives for 2022.

7.2 Proposed activities

Reported: As per notes on agenda.

8. APPROVAL OF 2020 PLANS AND SECRETARIAT

Agreed: Members approved five proposed plans for 2022 and the continuation of the Incisive Health Secretariat:

- Quantifying the rare disease backlog
- Health and Care Bill engagement
- Involving patients in medicines access reform
- Integrated Care Systems – impact on specialised services
- Reactivating the NICE Citizens' Council

9. FEEDBACK TO SECRETARIAT

10. GUEST SPEAKER

Reported: As per notes on agenda.

Eight 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.