

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE, MONDAY 8 JUNE 2020
(11.00 – 13.30) VIA VIDEO CONFERENCE**

Present:

Lord Sharkey - Chair
Baroness Chisholm - Vice Chair
Baroness Wheeler - Vice Chair

Adam Lloyd - Sickle Cell Society
Amanda Mortensen - Batten Disease Family Association
Anita Ralli - Gilead
Anna Evans - Cystic Fibrosis Trust
Bob Stevens - MPS Society
Brian Gunson - Liver4life
Charlotte Wickens - Anthony Nolan
Cheryl Gowar - National AIDS Trust
Chris Sotirelis - Patient representative for thalassaemia
Ciarán Scott - The AKU Society
Dan Betts - CSL Behring
Dave Bracher - Spinal Injuries Association
Deborah Bent - Limbless Association
Diane Splevings - Takeda
Fredi Cavander-Attwood - MS Society
Professor Gareth Morgan - The Children's Trust
Graham Coates - BioMarin
Jackie Imrie - Niemann-Pick UK
Jill Praver - LPLD Alliance
Josie Anderson - Bliss
Kate Downey - Janssen
Laura Szutowicz - HAE UK
Pat Roberts - ArchAngel MLD Trust
Rob Burley - Muscular Dystrophy UK
Robert Dalglish - Fanconi Hope Charitable Trust
Ropinder Gill - Lymphoma Association
Samantha Sharp - Kidney Care
Dr Sorrel Bickley - Sarcoma UK
Sue Farrington - Scleroderma & Raynaud's UK

Secretariat:

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

1. APOLOGIES

- Patricia Osborne - Brittle Bone Society UK

2. MINUTES

Reported: the minutes of the last meeting on Thursday 19 March were agreed and will be published on the SHCA's website. **Done**

3. MATTERS ARISING

3.1 Vice-Chair update

Reported: members confirmed the appointment of Baroness Chisholm as a new Vice Chair of the SHCA.

3.2 Secretariat update

Reported: James Maxwell has joined the Secretariat.

3.3 Membership update

Reported: since the last meeting on Thursday 19 March, Thyroid Eye Disease Charitable Trust have joined the SHCA.

4. KEY POLICY ISSUES

4.1 Coronavirus – impact on specialised services

Reported: as per notes on agenda.

Agreed: SHCA Secretariat to attend the forthcoming NHS England Stakeholder Forum meeting and feed in areas of concerns to members. **15.06.20**

Agreed: SHCA Secretariat to share the findings from the survey on members' experiences of care during the pandemic and priorities as services restart with NHS England. **12.06.20**

4.2 Political update

Reported: as per notes on agenda.

Agreed: SHCA Secretariat to continue to monitor developments on the Medicines and Medical Devices Bill. **Ongoing**

4.3 NHS recovery

Reported: as per notes on agenda.

Agreed: SHCA Secretariat to provide members with a written update on the phased approach to NHS recovery. **12.06.20**

4.4 Policy development and prioritisation process

Reported: as per notes on agenda.

Agreed: SHCA Secretariat to provide a further update on the delayed May Clinical Priorities Advisory Group (CPAG) prioritisation meeting following the Stakeholder Forum meeting. **19.06.20**

4.5 NICE reform

Reported: as per notes on agenda.

Agreed: members to feed into the SHCA Secretariat their views on whether the NICE methods review should be paused in light of the COVID-19 pandemic. **Ongoing**

Agreed: SHCA Secretariat to respond to planned consultations published by NICE. **As appropriate**

4.6 National Conversation on Rare Diseases

Reported: as per notes on agenda.

4.7 Devolved nations update

Reported: as per notes on agenda.

Agreed: SHCA Secretariat to seek feedback from members on access to the support packages offered to charities by the Scottish Government. **As appropriate**

4.8 Brexit

Reported: as per notes on agenda.

5. KEY ACTIVITY

5.1 Coronavirus – supporting the patient community

Reported: as per notes on agenda.

Agreed: SHCA Secretariat to share the results of the member survey on experiences of care during the COVID-19 pandemic and priorities as services restart. **As appropriate**

Agreed: members to continue to share their concerns around the financial implications of COVID-19 and access to support schemes they would like raised with relevant stakeholders. **Ongoing**

Agreed: SHCA Secretariat to share the areas of concern raised by members on changes to shielding guidance, and advice on personal protective equipment (PPE), with the

Department of Health and Social Care and NHS England, and to seek a meeting between the SHCA Chairs and Lord Bethell on this front. **Ongoing**

Agreed: SHCA Secretariat to explore issues surrounding the communication of guidance and advice to those on the shielding list, especially where individuals are removed without forewarning and the lack of consistency, and the use of do-not-resuscitate (DNR) orders. **As appropriate**

5.2 Update on Brexit

Reported: as per notes on agenda.

5.3 NICE reform

Reported: as per notes on agenda.

5.4 Making genomic healthcare a reality for patients

Reported: as per notes on agenda.

5.5 Bridging the social care gap

Reported: as per notes on agenda.

Agreed: SHCA Secretariat to continue to focus on social care in relation to COVID-19 as the short-term priority of the SHCA's advocacy on social care. **Ongoing**

6. GUEST SPEAKER

Reported: Richard Douglas, Chair of South East London Integrated Care System, was the guest speaker at the meeting.

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.