

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE, WEDNESDAY 9 JUNE 2021
(11:00-14:00) VIA VIDEOCONFERENCE**

Present:

Lord Sharkey - Chair

Baroness Chisholm - Vice Chair

Alex Massey - Motor Neurone Disease Association

Allan Muir - Pompe Support Network

Amanda Mortensen - Batten Disease Family Association

Amanda Swain - UK Acquired Brain Injury Forum

Andrea Sharples - Communication Matters

Andrew Gregory - Vertex

Bobby Ancil - Muscular Dystrophy UK

Bradley Price - Sarcoma UK

Brian Gunson - Liver4life

Caroline Morrice - Guillain Barre and Associated Inflammatory Neuropathies

Cheryl Gowar - National AIDS Trust

Chris Sotirelis - UK Thalassaemia Society

Ciarán Scott - AKU Society

Deborah Bent - Limbless Association

Deborah Flanagan - Gilead

Diane Splevings - Takeda

Frances Luff - Gilead

Graham Coates - BioMarin

Heather Delaney - Fibrous Dysplasia Support Society UK

Jackie Imrie - Niemann-Pick UK

Jeff Courtney - The Haemophilia Society

Jess Doyle - Metabolic Support UK

Jill Praver - LPLD Alliance

Joella Metcalfe - Niemann-Pick UK

Len Woodward - aHUS Alliance

Lesley Kavi - Postural Tachycardia Syndrome UK

Lisa Bashorum - Amicus Therapeutics

Liz Brownnutt - Batten Disease Family Association

Lynne Regent - Anaphylaxis Campaign

Markus Bell - Nerve Tumours UK

Michaela Regan - Cystic Fibrosis Trust

Niamh Buckingham - Sue Ryder

Patricia Osborne - Brittle Bone Society

Paul Farthing - The Children's Trust

Paul Pambakian - Takeda

Pete Revell - National Kidney Federation

Richard Gardner - Janssen UK

Ruth MacLeod - MS Society

Sam Mountney - Neurological Alliance

Sam Williams - The Aplastic Anaemia Trust
Samantha Barber - Gene People
Samantha Sharp - Kidney Care UK
Sue Dimmock - UK Primary Immune-deficiency Patient Support
Sujan Sivasubramaniyam - CSL Behring
Susan Passmore - PWSA UK
Susan Walsh - Immunodeficiency UK
Tess Harris - Polycystic Kidney Disease Charity
Dr Thomas Kenny - MPS Society
Vicky Hargreaves - Novartis
Victoria Wareham - The Dystonia Society
Yasmin Sheikh - Anthony Nolan

Secretariat:

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

1. APOLOGIES

- Baroness Wheeler - Vice Chair
- Amanda Mortensen, Batten Disease Family Association
- Andrea Brown, National Kidney Federation
- Andy Barrick, Multiple System Atrophy Trust
- Georgina Morton, ArchAngel MLD Trust
- John James, Sickle Cell Society
- Roger Greenwood
- Seyi Afolabi, Sickle Cell Society

2. MINUTES

Reported: The minutes of the last meeting on Wednesday 17 March 2021 were agreed and will be published on the SHCA's website. **Done**

3. MATTERS ARISING

3.1 Membership update

Reported: Since the last meeting on Wednesday 17 March, the Pompe Support Network has joined the SHCA.

4. HOUSE KEEPING

5. KEY POLICY ISSUES

5.1 Coronavirus

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to share member concerns with the Department of Health and Social Care on COVID-19 vaccine communications concerning vaccine certification for the immunocompromised. **Done**

5.2 NHS recovery

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to draft a response to the anticipated 2021 spending review consultation once it is published, feeding in the SHCA's priorities for NHS recovery. **As appropriate**

5.3 NHS structural changes

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to keep members informed of developments relating to the forthcoming Health and Care Bill. **Ongoing**

Agreed: SHCA Secretariat to write to the Department of Health and Social Care for representation in the development of NHS Digital's General Practice Data for Planning and Research (GPDPR) initiative. **June 2021**

5.4 Genome UK strategy – implementation

Reported: As per notes on agenda.

5.5 Devolved nations

Reported: As per notes on agenda.

5.6 NICE reform/Innovative Medicines Fund

Reported: As per notes on agenda.

Agreed: Members to share evidence on the impact of proposed changes to the high-cost drugs exclusion list in the 2021/22 national tariff on access to medicines. **Done**

Agreed: SHCA Secretariat to highlight concerns with NHS England and NHS Improvement on proposed changes to the high-cost drugs exclusion list in the 2021/22 national tariff. **Done**

6. KEY ACTIVITY

6.1 NHS England workshop on UK Rare Diseases Framework

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to share meeting materials in advance of the NHS England workshop on the development of the action plan for England for the UK Rare Diseases Framework, and communicate a summary of key themes following the meeting. **June 2021**

6.2 Integrated Care System NHS recovery stakeholder workshop

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to continue to update members on developments regarding the planned ICS NHS recovery stakeholder workshop, and engagement with the Federation of Specialist Hospitals survey. **Ongoing**

Agreed: Lord Sharkey to raise at his next meeting with NHS England the need for up-to-date national service specifications for those specialised services which Integrated Care Systems (ICSs) take on commissioning responsibilities for. **September 2021**

6.3 Access to medicines review

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to draft the access to medicines review in August to coincide with the publication of NICE's draft programme manual. **August 2021**

6.4 Parity of priority

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to share the briefing on the NHS Health and Care Bill with interested Parliamentarians ahead of debates on the legislation. **As appropriate**

7. LUNCH BREAK

8. GUEST SPEAKER

Reported: Lord Bethell of Romford, Parliamentary Under-Secretary of State for Innovation, was the guest speaker at the meeting.

9. ANY OTHER BUSINESS

Reported: The next quarterly members' meeting of the SHCA will take place on Wednesday 6 October 2021.

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.