

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE, WEDNESDAY 17 MARCH
2021 (11:00-13:00) VIA VIDEOCONFERENCE**

Present:

Lord Sharkey - Chair

Baroness Chisholm - Vice Chair

Alex Davis - Novartis

Alex Massey - Motor Neurone Disease Association

Amanda Mortensen - Batten Disease Family Association

Amanda Swain - UK Acquired Brain Injury Forum

Andrea Brown - National Kidney Federation

Andrea Sharples - Communication Matters

Andrew Hollingsworth - Vertex

Beth McCleverty - Bliss

Bob Stevens - MPS Society

Bobby Ancil - Muscular Dystrophy UK

Bradley Price - Sarcoma UK

Brian Gunson - Liver4life

Caroline Morrice - Guillain Barre and Associated Inflammatory Neuropathies

Charlotte Martin - Leukaemia Care

Chris Sotirelis - UK Thalassaemia Society

Ciarán Scott - AKU Society

Dan Betts - CSL Behring

Dave Bracher - Spinal Injuries Association

Deborah Flanagan - Gilead

Diane Splevings - Takeda

Fredi Cavander-Attwood - MS Society

Heather Delaney - Fibrous Dysplasia Support Society UK

Jackie Guyler - Spinal Muscular Atrophy UK

Jamie White - Cystic Fibrosis Trust

Jane Lyons - Cancer52

Jeff Courtney - The Haemophilia Society

Jill Praver - LPLD Alliance

Jo Bullingham - PoTS UK

Joella Melville - Niemann-Pick UK

John James - Sickle Cell Society

Katharine McIntosh - Neurological Alliance

Laura Szutowicz - HAE UK

Luis Guerra - Gilead

Margaret Allan - Metabolic Support UK

Michaela Regan - Cystic Fibrosis Trust

Neil Rowntree - PNH Support

Patricia Osborne - Brittle Bone Society

Paul Farthing - The Children's Trust

Paul Pambakian - Takeda

Pete Revell - National Kidney Federation
Richard Gardner - Janssen UK
Roger Greenwood - NHS England
Ruth MacLeod - MS Society
Samantha Barber - Tuberous Sclerosis Association
Samantha Sharp - Kidney Care UK
Sonia Allen - The Children's Trust
Sue Dimmock - UK Primary Immunodeficiency Patient Support
Sujan Sivasubramaniam - CSL Behring
Susan Passmore - PWSA UK
Tina Nesbitt - AGS UK network
Victoria Wareham - The Dystonia Society
William Highfield - Novartis
Yasmin Sheikh - Anthony Nolan

Secretariat:

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

1. APOLOGIES

- Baroness Wheeler - Vice Chair
- Arlene Smyth - Turner Syndrome Support Society (UK)
- Jane Lewthwaite - AGSD-UK
- Jo Bullingham - PoTS UK
- Liz Ryburn - Spinal Muscular Atrophy UK
- Lynne Regent - Anaphylaxis Campaign
- Professor Gareth Morgan - The Children's Trust

2. MINUTES

Reported: The minutes of the last meeting on Wednesday 20 January 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 20 January, the AGS UK network has joined the SHCA.

4. KEY POLICY ISSUES

4.1 NHS legislative proposals

Reported: As per notes on agenda.

Reported: Lord Sharkey provided an overview of his meeting with Health Minister Lord Bethell on the Government's NHS White Paper, *Integration and innovation: working together to improve health and social care for all*, where he sought reassurances over areas of the White Paper of interest to the SHCA, including in relation to the devolution of commissioning responsibilities of certain specialised services to Integrated Care Systems.

Agreed: SHCA Secretariat to share a draft response with members to the Health and Social Care Select Committee's inquiry into the NHS White Paper for feedback. **Done**

4.2 UK Rare Diseases Framework – national action plans

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to seek an update from Lord Bethell on England's National Action Plan during his appearance at the June quarterly members' meeting. **June 2021**

4.3 Coronavirus

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to share member concerns with the Department for Health and Social Care on COVID-19 vaccine communications in relation to the immune response generated by cancer patients. **Done**

4.4 NHS recovery

Reported: As per notes on agenda.

4.5 NICE reform/Innovative Medicines Fund

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to share a draft response to the NICE processes consultation for members' input. **March 2021**

Agreed: SHCA Secretariat to keep members informed of developments relating to the Innovative Medicines Fund and seek members' input in response to NHS England's upcoming consultation on the Fund. **Ongoing**

Agreed: SHCA Secretariat to draft a response to the consultation once it is live. **As appropriate**

5. KEY ACTIVITY

5.1 Policy report on establishing links between specialised and community services

Reported: As per notes on agenda.

Agreed: Members to comment and share views on the policy report shared by the Secretariat by 19 March 2021. **Done**

5.2 Integrated Care System NHS recovery stakeholder workshop

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to write to members on participation and involvement in the proposed workshop. **As appropriate**

5.3 Access to medicines review

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to share an outline structure for the review in advance of the June quarterly members' meeting. **June 2021**

5.4 Parity of priority

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to explore lessons from Hertfordshire and West Essex ICS's patient involvement strategy. **April 2021**

Agreed: SHCA Secretariat to align with National Voices on key asks of the forthcoming Bill on the NHS White Paper. **May 2021**

6. GUEST SPEAKER

Reported: Richard Murray, Chief Executive of The King's Fund, 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.