

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE, WEDNESDAY 20 JANUARY
2021 (11.00-14.00) VIA VIDEOCONFERENCE**

Present:

Lord Sharkey - Chair

Baroness Wheeler - Vice Chair

Baroness Chisholm - Vice Chair

Adam Lloyd - Sickle Cell Society

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

Andy Gregory - Vertex

Anna Evans - Cystic Fibrosis Trust

Arlene Smyth - Turner Syndrome Support Society (UK)

Beth McCleverty - Bliss

Bob Stevens - MPS Society

Bobby Ancil - Muscular Dystrophy UK

Brian Gunson - Liver4life

Charlotte Galvin - Amicus Therapeutics

Cheryl Gowar - National AIDS Trust

Ciarán Scott - AKU Society

Dan Betts - CSL Behring

Deborah Bent - Limbless Association

Deborah Flanagan - Gilead

Diane Splevings - Takeda

Edward Potter - CSL Behring

Fredi Cavander-Attwood - MS Society

Professor Gareth Morgan - The Children's Trust

Graham Coates - BioMarin

Jackie Imrie - Niemann-Pick UK

Jane Lyons - Cancer52

Jayne Bressington - GIST Cancer UK

Jeff Courtney - The Haemophilia Society

Joseph Brunwin - MS Society

Katharine McIntosh - Neurological Alliance

Kerry Leeson-Beevers - Alstrom Syndrome |UK

Louisa Dallas - Novartis

Louise Fish - Tuberous Sclerosis Association

Lynne Regent - Anaphylaxis Campaign

Michaela Regan - Cystic Fibrosis Trust

Neil Rowntree - PNH Support

Niamh Buckingham - Sue Ryder

Patricia Osborne - Brittle Bone Society

Paul Farthing - The Children's Trust
Paul Pambakian - Takeda
Pushpa Hossain - Metabolic Support UK
Ruth MacLeod - MS Society
Stevie Tyler - The Aplastic Anaemia Trust
Sue Dimmock - UK Primary Immune-deficiency Patient Support
Sujan Sivasubramaniyam - CSL Behring
Tony Griffiths - St Andrew's Healthcare
Yasmin Sheikh - Anthony Nolan

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

- John James, Sickle Cell Society
- Tess Harris, PKD Charity

2. MINUTES

Reported: The minutes of the last meeting on Monday 5 October 2020 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 Monday 5 October, Leukaemia Care has joined the SHCA.

4. KEY POLICY ISSUES

4.1 Coronavirus

Reported: As per notes on agenda.

Agreed: Members to feed into the SHCA Secretariat their views on how COVID-19 policy has affected people with rare and complex conditions, including concerns regarding financial support packages. **Ongoing**

Agreed: Lord Sharkey to write to Lord Bethell, Parliamentary Under-Secretary of State for Innovation, requesting additional guidance about the vaccination programme for rare and less common health conditions. **Done**

4.2 NHS England and Improvement ICS proposals

Reported: As per notes on agenda.

Reported: The Government is expected to present draft legislation to restructure the NHS before Parliament in the summer.

4.3 UK Rare Diseases Framework

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to write to the devolved administrations of the UK regarding the development of nation-specific action plans following the publication of the Framework.
January 2021

4.4 NICE reform

Reported: As per notes on agenda.

4.5 Devolved nations update

Reported: As per notes on agenda.

4.6 Brexit

Reported: As per notes on agenda.

Reported: Following parliamentary scrutiny of the Medicines and Medical Devices Bill, the Government has committed to introducing a Patient Safety Commissioner for England who will promote the voice of patients on safety. The Bill is in the final stages of the legislative process.

5.5. KEY ACTIVITY

5.1 Integrated Care System NHS recovery stakeholder workshop

Reported: As per notes on agenda.

5.2 Policy report on establishing links between specialised and community services

Reported: As per notes on agenda.

5.3 Access to medicines review

Reported: As per notes on agenda.

5.4 Parity of priority

Reported: As per notes on agenda.

Agreed: SHCA Secretariat to provide members with an update on the Government's plans to reform the Mental Health Act. **January 2021**

6. GUEST SPEAKER

Reported: Gareth Arthur, Director of Policy and Strategy in the Specialised Commissioning Directorate at NHS England and Improvement, 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.