

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE, MONDAY 5 OCTOBER 2020
(11.00 – 14.00) VIA VIDEOCONFERENCE**

Present:

Lord Sharkey – Chair
Baroness Chisholm – Vice Chair

Alex Massey - Motor Neurone Disease Association
Amanda Mortensen- Batten Disease Family Association
Andrea Brown - National Kidney Federation
Anita Ralli - Gilead Sciences
Arlene Smyth - Turner Syndrome Support Society
Beth McCleverty - Bliss
Bob Stevens - MPS Society
Brian Gunson - Liver4life
Charlotte Wickens - Anthony Nolan
Cheryl Gowar – National AIDS Trust
Christos Sotirelis - UK Thalassaemia Society
Ciarán Scott - AKU Society
Deborah Flanagan - Gilead Sciences
Graham Coats - BioMarin
Jamie White - Cystic Fibrosis Trust
Jane Lewthwaite - Association for Glycogen Storage Disease
Jo Bullingham - PoTS UK
Jonathan Kelly - Beat
Joseph Brunwin - MS Society
Judith Abel - Neurological Alliance
Kate Downey – Janssen UK
Laura Cockram - Parkinson's UK
Len Woodward - aHUS Alliance
Lisa Bashorum - Amicus Therapeutics
Mary-Beth Peddell - Novartis Pharmaceuticals
Michaela Regan - Cystic Fibrosis Trust
Neil Roundtree - PNH Support
Niamh Buckingham - Sue Ryder
Nigel Nicholls - BioMarin
Pat Roberts - ArchAngel MLD Trust
Patricia Osborne - Brittle Bone Society
Professor Gareth Morgan - The Children's Trust
Robert Burley - Muscular Dystrophy UK
Samantha Sharp - Kidney Care UK
Sarah Hunt - Alex, The Leukodystrophy Charity
Steve Bojakowski - Sobi
Stevie Tyler - The Aplastic Anaemia Trust
Sue Farrington - Scleroderma & Raynaud's UK
Susan Passmore - PWSA UK
Victoria Wareham - The Dystonia Society

Secretariat:

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

1. APOLOGIES

- Baroness Wheeler – Vice Chair
- Victoria Wareham, Dystonia UK
- Deborah Bent, Limbless Association

2. MINUTES

Reported: the minutes of the last meeting on Monday 8 June 2020 were agreed and will be published on the SHCA's website. **Done**

3. CORPORATE SUPPORTERS UPDATE

Agreed: Vertex were confirmed as a Corporate Supporter of the Alliance.

Reported: Members would like to thank its Corporate Supporters for their continued support of the Alliance in 2020.

4. KEY POLICY ISSUES

4.1 Coronavirus

Reported: as per notes on agenda.

4.2 NHS recovery

Reported: as per notes on agenda.

Agreed: Members to feedback on any specific areas where capacity has been reduced compared to pre-pandemic levels. **Ongoing**

Agreed: SHCA Secretariat to raise with NHS England any specific concerns identified by members regarding services operating at less than the national target for service activity. **As appropriate**

4.3 Rare disease strategy

Reported: as per notes on agenda.

4.4 NICE reform

Reported: as per notes on agenda.

4.5 Brexit

Reported: as per notes on agenda.

Agreed: SHCA Secretariat to monitor developments regarding the future of European Reference Networks (ERNs) in light of ongoing UK and EU negotiations. **Ongoing**

4.6 Devolved nations update

Reported: as per notes on agenda.

5. KEY ACTIVITY

5.1 Support for SHCA members on coronavirus

Reported: as per notes on agenda.

5.2 Medicines and Medical Devices Bill

Reported: as per notes on agenda.

Reported: Lord Sharkey provided an overview of the Government's plans for the Bill and outlined the main areas of contention in the House of Lords, including amendments over scrutiny, patient safety, clinical trial regulation, and consultation.

5.3 NHS England Stakeholder Forum

Reported: as per notes on agenda.

Agreed: SHCA Secretariat to reach out to members for feedback ahead of the November meeting of the NHS England Stakeholder Forum

5.4 Social care engagement

Reported: as per notes on agenda.

Agreed: Members to share case studies that highlight the need for social care reform as part of a media story, alongside the letter from the Alliance to the Secretary of State for Health and Social Care.

6. 2021 PLANS

6.1 Proposed objectives and strategy for 2020

Reported: the SHCA Secretariat updated members on its plans and objectives for 2020.

6.2 Proposed activities:

Reported: as per notes on agenda.

Reported: in 2021, the SHCA Secretariat provided an update on a longlist of proposed projects to be undertaken in 2021.

7. APPROVAL OF 2020 PLANS AND SECRETARIAT

Agreed: Members approved three proposed plans for 2021 and the continuation of the Incisive Health Secretariat:

- Integrated Care System NHS recovery stakeholder workshop
- Policy report on establishing links between specialised and community services
- Access to medicines review

Agreed: Members to provide any additional feedback to the SHCA Secretariat. **As appropriate**

8. LUNCH BREAK

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.