

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE, MONDAY 20 JANUARY
2020 (11.00 – 14.00) IN THE ARCHBISHOPS ROOM, MILLBANK HOUSE, LITTLE
COLLEGE STREET, LONDON, SW1P 3SH**

Present:

Lord Sharkey – Chair
Baroness Penn – Vice Chair
Baroness Wheeler – Vice Chair

Anna Evans - Cystic Fibrosis Trust
Bradley Price - Sarcoma UK
Chris Sotirelis - Patient representative for thalassaemia
Ciarán Scott - AKU Society
David Ryner - Chronic Myeloid Leukaemia Support Group
Deborah Bent - Limbless Association
Deborah Flanagan - Gilead
Grazina Berry - The Aplastic Anaemia Trust
James Fitzpatrick - Actelion
Jayne Bressington - GIST Support UK
Jerome Penn – Takeda
John James – Sickle Cell Society
Jonathan Kingsley - Muscular Dystrophy UK
Len Woodward - aHUS Alliance
Louise Fish - Tuberous Sclerosis Association
Luke Fraser - Patient representative for AGSD
Mary-Beth Peddell - Novartis
Nigel Nicholls - BioMarin
Patricia Osborne - Brittle Bone Society
Professor Gareth Morgan - The Children's Trust
Samantha Sharp - Kidney Care UK
Victoria Wareham - The Dystonia Society

Secretariat:

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

1. APOLOGIES

- Andy Barrick - MSA Trust
- Lynne Regent - Anaphylaxis Campaign

2. MINUTES

Reported: the minutes of the last meeting on Wednesday 9 October 2019 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 Penn as a new Vice Chair of the SHCA.

3.2 Secretariat update

Reported: Catarina Casella and Claire Hastings have joined the Secretariat.

4. KEY POLICY ISSUES

4.1 Political update

Reported: as per notes on agenda.

Reported: the SHCA Secretariat provided an update on the health-related bills expected in the Commons.

4.2 NHS Long Term Plan implementation

Reported: as per notes on agenda.

Agreed: SHCA Secretariat to provide members with an update on the National Implementation Framework of the NHS Long Term Plan when it is published, as well as other publications in relation to the implementation of the Long Term Plan. **As appropriate**

Agreed: SHCA Secretariat to continue engagement with NHS England following the publication of the Framework, including on opportunities for patient groups to engage with local stakeholders around the local implementation plans developed by Sustainability and Transformation Partnerships/Integrated Care Systems. **As appropriate**

Agreed: SHCA Secretariat to update members on developments around NHS England's reforms to waiting times, and to make a decision on possible activity in this area at the next

quarterly meeting. **19.03.20**

4.3 Prioritisation process

Reported: as per notes on agenda.

Agreed: SHCA Secretariat to continue to engage with NHS England on:

- The introduction of public meetings of the Clinical Priorities Advisory Group (CPAG), and opportunities for expert input into the meetings
- The need for a consultation on individual treatments to be 90 days in length to allow for sufficient time for feedback from providers and patient groups
- What criteria is used to determine when a consultation on individual treatments is held
- The need for a consultation on the transferring of responsibilities to NICE on the assessment of certain treatments within specialised commissioning, to gain input from stakeholders. **Ongoing**

4.4 National Conversation on Rare Diseases

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.

Agreed: SHCA to write to Baroness Blackwood outlining members' concerns around the UK's proposed regulatory divergence from the European Union post Brexit for rare diseases, focusing on the expected impact on clinical trials and on medicines authorisation. **31.01.20**

5. KEY ACTIVITY OVER THE LAST QUARTER

5.1 Exploring the growing differences in access policy across the UK

Reported: as per notes on agenda.

Agreed: SHCA Secretariat to upload the final version of the report onto the SHCA website.
Done

5.2 Developing an SHCA position on health technology appraisal reform in England

Reported: as per notes on agenda.

Agreed: SHCA Secretariat to upload both the summary and full version of the report onto the

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SHCA website. **Done**

6. PROPOSED PROJECTS FOR 2020

6.1 Raising the volume on NICE reform

Reported: as per notes on agenda.

Agreed: SHCA Secretariat to develop the toolkit to help members engage with NICE reform ahead of the consultation on the NICE methods review, expected in the summer of 2020.

March 2020

Agreed: SHCA Secretariat to draft a template letter to relevant APPGs as part of the toolkit.

March 2020

6.2 Bringing to life the impact of Brexit on rare and complex conditions

Reported: as per notes on agenda.

Agreed: SHCA Secretariat to send an email to SHCA members asking if they would have 30 minutes to discuss their views on what is required from a future UK-EU trade deal, and the issues they are most concerned with. **January 2020**

Agreed: Interested members to respond to the email and engage with the Secretariat, to support the development of a short report to be shared with Ministers and the media. **February 2020**

6.3 Making genomic healthcare a reality for patients

Reported: as per notes on agenda.

Agreed: SHCA Secretariat to carry out a listening exercise of members' views on the NHS Genomic Medicine Service. **March 2020**

Agreed: SHCA Secretariat to engage with the DHSC, NHS England and NICE on the impact of uncertainty around progress on the NHS Genomic Medicine Service. **February 2020**

6.4 Bridging the social care gap

Reported: as per notes on agenda.

6.5 Measuring patient involvement in the future NHS

Reported: as per notes on agenda.

Agreed. As part of the listening exercise with members on challenges in engaging with specialised commissioning teams, members to feedback on their experiences in engaging

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with Clinical Reference Groups (CRGs), and any barriers to engagement they have faced.
As appropriate

7. LUNCH

8. GUEST SPEAKER

Reported: Gareth Arthur, Director of Strategy and Policy for Specialised Services at NHS England, and Ellen Graham, Deputy Director, Genomics, were the guest speakers 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.