

MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE FROM 11.00 – 14.00 ON WEDNESDAY 10 JANUARY 2018 IN COMMITTEE ROOM G, HOUSE OF LORDS

Present:

Lord Sharkey - Chair

Adam Lloyd - Sickle Cell Society
Andy Barrick - Multiple System Atrophy Trust
Carina Righetti - Actelion
Caroline Weston - Clic Sargent
Chris Sotirelis - Patient representative for thalassaemia
Christopher Hicks - National AIDS Trust
Ciarán Scott - AKU Society
Claudia Rubin - PHA UK
Dan Betts - CSL Behring
Dan Burden - Spinal Injuries Association
David Martin - MS Trust
David Ryner - Chronic Myeloid Leukaemia Support Group
David Stokes - Cleft Lip & Palate Association
Fiona Loud - Kidney Care UK
Hassan Abu-Bakir - Fight for Sight
Luke Ashton - Merck
Jack Doughty - MS Society
Jeff Courtney - The Haemophilia Society
Jerome Penn - Pfizer
Katharine McIntosh - Neurological Alliance
Len Woodward - aHUS UK
Margaret Gould - The British Society for Rheumatology
Matina Loizou - Parkinson's UK
Meriel Miller - The Children's Trust
Nigel Nicholls - BioMarin Pharmaceutical
Patricia Osborne - Brittle Bone Society
Paul Decle - The Forum Link Project
Roger Brown - Waldenström's Macroglobulinemia UK
Simon Butler - Anthony Nolan
Steve Bojakowski - Sobi

Secretariat:

Bill Morgan - SHCA Secretariat
Ed McIntosh - SHCA Secretariat
Elizabeth Beck - SHCA Secretariat
Maddy Farnworth - SHCA Secretariat
Klark Mullen - SHCA Secretariat

1. GUEST SPEAKER

Reported: as per notes on agenda.

Agreed: Members to contact Andrew Dillon directly with any concerns they have about NICE processes.

2. APOLOGIES

- Baroness Wheeler - Vice Chair
- Brian Gunson - British Liver Trust
- Patricia Osbourne - Brittle Bone Society
- Beth McCleverty - Bliss
- Diane Splevings - Shire
- Gary Jones - AbbVie
- Jane Lyons - Cancer52
- Jill Praver - LPLD Alliance
- Liz Macartney - UKPIPs
- Pat Roberts - Save Babies UK
- Tess Harris - PKD Charity
- Sue Farrington - Scleroderma & Raynaud's UK

3. MINUTES

Reported: the minutes of the last all members meeting on Wednesday 11 October 2017 and the meeting with Lord O'Shaughnessy on 29 November were agreed and will be published on the SHCA's website. **Done**

4. MATTERS ARISING

4.1 Membership and Corporate Supporters update

Reported: The SHCA would like to welcome BioMarin and recall its thanks to the SHCA's other Corporate Supporters for their support of the Alliance in 2018.

4.2 Secretariat update

Reported: Maddy Farnworth has joined the SHCA Secretariat.

5. KEY POLICY ISSUES

5.1 Winter pressures

Reported: SHCA Secretariat met with NHS England, who asked for examples of access to specialised services being limited due to winter pressures.

Reported: Spinal Injuries Association reported that Stoke Mandeville Hospital's Spinal Injury unit had been closed for bed escalations.

Reported: Kidney Care UK has heard of Dialysis Unit beds being closed to make way for emergency access.

Reported: Better guidance on flu and pneumococcal vaccinations for immunocompromised patients would be appreciated.

Agreed: SHCA Secretariat to share examples of specialised services affected by winter pressures with NHS England. **Done**

5.2 Cabinet Reshuffle

Reported: Jeremy Hunt remains Secretary of State for Health, but his remit and job title now includes Social Care. Lord O'Shaughnessy remains Parliamentary Under Secretary of State for Health. Two new ministers, Caroline Dinenage and Stephen Barclay, were announced.

Agreed: SHCA Secretariat to share details of ministerial responsibilities once announced. **Done**

5.3 Patient and public involvement – Specialised Commissioning Stakeholder Forum

Reported: as per notes on agenda.

Agreed: SHCA to circulate the NHS England video on the prioritisation process and communication with stakeholders. **Done**

5.4 Patient and public involvement – Specialised commissioning reform update

Reported: as per notes on agenda.

Agreed: SHCA Secretariat to circulate details of NHSE's implementation plans once available. **Ongoing**

5.5 UK Strategy for Rare Diseases

Reported: as per notes on agenda.

Reported: The ministerial reshuffle may impact timelines for the implementation plans if there are any changes in the division of ministerial responsibilities.

Agreed: SHCA Secretariat to circulate implementation plans when published. **Ongoing**

5.6 Access to treatments – Results of November prioritisation round

Reported: as per notes on agenda.

Agreed: SHCA Secretariat to explore when recommendations from May Prioritisation round will be funded at the next Specialised Commissioning Stakeholder Forum. **Date TBC**

Agreed: SHCA Secretariat to share details of CPAG and RDAG Chair vacancies. **Done**

5.7 Access to treatments – Commissioning Support Programme

Reported: as per notes on agenda.

5.8 Access to treatments – Scotland and the Montgomery Review

Reported: as per notes on agenda.

Reported: it was reported that the implementation of the Montgomery Review could result in delays to appraisals in Scotland.

Agreed: SHCA Secretariat to explore delays in the appraisal of treatments and seek further information on the outstanding recommendation yet to be implemented as part of the Scottish Government's phased implementation of the Montgomery Review. **19.01.18**

5.9 Industrial Strategy White Paper

Reported: as per notes on agenda.

Reported: Further sector deals are expected in the next six months.

5.10 Brexit

Reported: as per notes on agenda.

Reported: Members still had concerns over transportation of blood plasma, access to European Reference Networks and the transposition of EU legislation on the movement of treatments to non-transportable patients into UK law.

Reported: House of Lords to debate Withdrawal Bill at the end of January.

Agreed: Secretariat to express members' ongoing concerns with the Department of Health.
Done

6. KEY ACTIVITY OVER THE LAST QUARTER

6.1 Developing the SHCA's contribution to policy – Lord O'Shaughnessy meeting

Reported: as per notes on agenda.

Agreed: Secretariat to draft follow up note to Lord O'Shaughnessy focussing on transparency of the prioritisation process and patient participation. **28.01.18**

Agreed: Secretariat to seek members' endorsement of the letter. **28.01.18**

6.2 Developing the SHCA's contribution to policy – Labour Lords meeting

Reported: as per notes on agenda.

6.3 Developing the SHCA's contribution to policy – UK Strategy for Rare Diseases

Reported: as per notes on agenda.

7. LUNCH

8. PROPOSED ACTIVITIES FOR 2018

8.1 Think-piece on rare diseases

Reported: as per notes on agenda.

Agreed: SHCA Secretariat to begin work and provide an update in March meeting. **21.03.18**

Agreed: SHCA Secretariat to liaise with Rare Disease UK to seek to align with projects on access to rare disease treatments. **Ongoing**

8.2 Access to treatment “one year on”

Reported: as per notes on agenda.

Agreed: SHCA Secretariat to begin work and provide an update at March meeting. **21.03.18**

9. 2017 METRICS

9.1 2017 year-end information

Reported: as per notes on agenda.

10. 2018 CONFERENCE

10.1 Conference options

Reported: as per notes on agenda.

Reported: Previous conferences involved a nominal charge for charity attendees.

Agreed: Explore a potential partnership opportunity with NHS England to minimise costs, maximise attendance and ensure that any conference/session with NHS England must give opportunity to hear from people with rare diseases. **Ongoing**

11. ANY OTHER BUSINESS

Agreed: Date of March meeting confirmed as Wednesday 21 March 2018. **Done**