

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE FROM 11.00 – 14.00 ON
WEDNESDAY 12 JULY 2017 IN THE ARCHBISHOPS' ROOM AT MILLBANK HOUSE,
MILLBANK, LONDON, SW1P 3JU**

Present:

Lord Sharkey – Chair
Baroness Wheeler – Vice–Chair
Baroness Redfern – Vice–Chair

Alex Davison – Ashtma UK
Amelia Chong – Anthony Nolan
Anne Keatley–Clarke – Children’s Heart Foundation
Brian Gunson – British Liver Trust
Caroline Stickland – Bliss
Chris Sotirelis – UK Thalassaemia Society
Christopher Hicks – National AIDS trust
Ciarán Scott – AKU Society
David Ryner – CML Support Group
Deborah Flanagan – Gilead
Diane Splevings – Shire
Edward Nickell – Specialist Orthopaedics Alliance
Elaine Cooper – Neurological Alliance
Emma Barnes – The Children’s Trust
Fiona Loud – British Kidney Patient Association
Isabel Wilkinson – Teenage Cancer Trust
Jane Lyons – Cancer52
Jerome Penn – Pfizer
Jill Praver – LPLD Alliance
John James – Sickle Cell Society
Jonathan Blades – MS Society
Kate Downey – Actelion
Louisa Dallas – Novartis
Natalie Eudelle – Brittle Bone Society
Priyanka Patel – CLIC Sargent
Rachel Power – The Patients Association
Richard Rogerson – Niemann–Pick UK
Steve Bojakowski – Sobi

Secretariat:

Bill Morgan – SHCA Secretariat
Ben Nunn – SHCA Secretariat
Elizabeth Beck – SHCA Secretariat
Aalia Kazi – SHCA Secretariat
Klark Mullen – SHCA Secretariat

1. APOLOGIES

- Caroline Morris – Guillain Barre and Associated Inflammatory Neuropathies
- Liz Carroll – The Haemophilia Society
- Louise Fish – Tuberous Sclerosis Association
- Luke Ashton – Merck Group
- Lynne Regent – Anaphylaxis Campaign
- Maria Piggitt – PNH Support
- Matina Loizou – Parkinson's UK
- Pat Roberts – Save Babies Through Screening Foundation UK
- Sue Farrington – Scleroderma & Raynaud's UK

2. MINUTES

Reported: the minutes of the last meeting on Wednesday 29 March 2017 were agreed and will be published on the SHCA's website.

3. MATTERS ARISING

3.1 Membership update

Reported: Cancer 52 and The Patients Association have joined as new members.

3.2 Note on gene therapy

Reported: The Secretariat reported that one source of further reading on gene therapy is the NICE [paper](#) which sets out its emerging position on the assessment and appraisal of gene therapies.

Agreed: The Secretariat to keep a watching brief on the subject.

3.3 Secretariat update

Reported: as per notes on agenda.

4. ACTIVITY UPDATE

4.1 Chair's meeting with NHS England – 15 June

Reported: Lord Sharkey and members of the Secretariat held a teleconference with John Stewart, Acting Director of Specialised Commissioning, and Gareth Arthur, Head of Strategy & Policy, Specialised Commissioning, at NHS England to discuss a range of topics. The quarterly meetings will continue.

The meeting was structured around four areas of discussion: Patient and public involvement in specialised commissioning, NHS reform, access to treatment and the rare disease implementation plan.

Noted: When discussing NHS reform, Lord Sharkey noted that the Data Protection Bill and the Government's response to the Caldicott report are expected to undergo parliamentary scrutiny in the Autumn. He also said it was unlikely there would be any broader legislative

changes to the health and care system in the immediate future.

Reported: It was reported that last month NICE officials announced that the organisation will be participating in a new research project which aims to explore how quality-adjusted life-years (QALYs) might capture the benefits of treatment beyond health-related quality of life, such as independence or improved relationships with friends, family and carers.

Agreed: It was agreed that the Secretariat will share details with members and monitor the project because if its findings were used to extend NICE's QALY criteria, they would have a significant impact on the approval process.

Reported: The Secretariat informed members that the first meeting of the Specialised Commissioning Stakeholder Forum would take place on 13 July.

Agreed: The Secretariat to share papers for the meeting. The Secretariat to attend and to reflect members' queries about the Forum's future role, purpose and current membership.

4.2 Place-based commissioning workshop – 26 June

Reported: The meeting explored NHS England's vision for place-based commissioning of specialised services, which will initially see all STP areas have 'seat at the table' arrangements by April 2018.

There was a consensus that NHS England needs to be able to better communicate the benefits of place-based commissioning to patients and NHS England recognised that future workshops would be necessary to enable progress to be made on the issues raised.

Agreed: The Secretariat will share NHS England's summary of the meeting when it is made available and inform members of further opportunities to engage.

4.3 The Medical Supplies Bill has become law

Reported: as per notes on agenda.

4.4 Speaking out against unfair rationing decisions

Reported: as per notes on agenda.

4.5 Campaigning for manifesto commitments on access to treatment

Reported: as per notes on agenda.

4.6 Engagement with the Greater Manchester Combined Authority (GMCA)

Reported: The Secretariat remarked that the main barriers to a significant delegation of control over specialised services to Greater Manchester might be political rather than legal in their nature.

Agreed: Members to inform the Secretariat should they wish to participate in the meeting with Jon Rouse, Chief Officer of the GMCA, on 3 October. The Secretariat will provide members with a pre-briefing closer to the meeting date.

5. PARLIAMENTARY UPDATE

5.1 General Election 2017

Reported: as per notes on agenda.

Noted: Members noted that political uncertainty following the 2017 General Election could impact on NHS England accountability.

Agreed: The Secretariat will consider opportunities for how we can raise the issue of access to medicines in the new Parliament.

5.2 The Queen's Speech

Reported: as per notes on agenda.

5.3 Ministers and Shadow Ministers

Reported: The Secretariat remarked that the re-appointments of Jonathan Ashworth MP and Lord O'Shaughnessy are positive in view of the SHCA's previous engagement with the former and future engagement with the latter.

Noted: Lord Sharkey noted that data related matters fall under Lord O'Shaughnessy's ministerial portfolio.

6. POLICY UPDATE

6.1 Treatment appraisal process

Reported: About NHS England / NICE reform, NHS England expects five to ten treatments to trigger the affordability test each year. The changes to the highly specialised technology (HST) programme are yet to be triggered within an appraisal.

Noted: In response to a question from a member, it was noted that the previous HST programme is ongoing.

Reported: The Secretariat also reported that PPRS negotiations are expected to begin in December 2017 ahead of the current PPRS expiry in December 2018.

6.2 Implementation of UK Strategy for Rare Diseases

Reported: as per notes on agenda.

Considered: The meeting arranged with Fiona Marley, Head of Specialised Commissioning at NHS England, on 31 July is a good opportunity to discuss the implementation of the UK Strategy for Rare Diseases in England.

Agreed: Members to inform the Secretariat should they wish to participate in the meeting. The Secretariat will provide members with a pre-brief closer to the meeting date.

7. PROPOSED CHANGES TO QUARTERLY MEETING STRUCTURE

Reported: as per notes on agenda.

Agreed: Members accepted the proposed changes which will come into effect at the next meeting on 11 October.

8. LUNCH GUEST: JOHN STEWART, ACTING DIRECTOR OF SPECIALISED COMMISSIONING, NHS ENGLAND

Reported: as per notes on agenda.

Agreed: John Stewart agreed to continue to maintain the dialogue between NHS England and the SHCA.

Agreed: Lord Sharkey to write to John Stewart to clarify the scope of the specialised services stakeholder forum.