

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE FROM 11.00 – 14.00 ON
WEDNESDAY 29 MARCH 2017 IN THE ASHLEY COOPER ROOM AT THE ABBEY
CENTRE, 34 GREAT SMITH STREET, LONDON, SW1P 3BU**

Present:

Lord Sharkey – Chair
Baroness Wheeler – Vice-Chair

Brian Gunson – British Liver Trust
Catherine Hodder – Young Epilepsy
Chris Sotirelis – Patient representative for thalassaemia
Ciaran Scott – AKU Society
Dan Rattigan – MS Society
David Stokes – Cleft Lip & Palate Association
Debra Morgan – Pfizer
Diane Splevings – Shire
Fiona Loud – British Kidney Patient Association
Marie-Claire – Ovarian Cancer Action
Jill Praver – LPLD Alliance
John James – Sickle Cell Society
Joseph Clift – Asthma UK
Laura Szutowicz – HAE UK
Richard Rogerson – Niemann-Pick UK
Roger Brown – Waldenström's Macroglobulinemia UK
Sarah Hutchinson – National Voices
Sasha Daly – Teenage Cancer Trust
Simon Butler – Anthony Nolan
Steve Bojakowski – Sobi
Tanya Collin – Histed-Gauchers Association
Tess Harris – Polycystic Kidney Disease Charity
Alex Massey – Motor Neurone Disease Association
Priyanka Patel – CLIC Sargent
Darren O'Keefe – Cystic Fibrosis Trust
Stephen Hoffman – Action Duchenne
Elaine Cooper – Neurological Alliance
Jack Feinmann – The British Society for Rheumatology
Christopher Hicks – National AIDS Trust
Peter Sutton – Muscular Dystrophy UK

Secretariat:

Bill Morgan – SHCA
Ben Nunn – SHCA
Ed McIntosh – SHCA
Elizabeth Beck – SHCA
Aalia Kazi – SHCA

1. GUEST SPEAKER

Reported: as per notes on agenda.

Agreed: Members who discussed the opportunity to meet with Jonathan Ashworth MP to liaise with secretariat over contact details.

2. APOLOGIES

- Baroness Redfern, Vice-Chair
- Caroline Morrice, Guillain Barre and Associated Inflammatory Neuropathies
- Gary Jones, AbbVie
- Jerome Penn, Pfizer
- Laura Cockram, Parkinson's UK
- Lynne Regent, Anaphylaxis Campaign
- Maria Piggin, PNH Support
- Meriel Miller, The Children's Trust
- Pat Roberts, Save Babies UK
- Patricia Osborne, Brittle Bone Society
- Patrick O'Jeer
- Matthew Hawthorne, AbbVie

3. MINUTES

Reported: the minutes of the last meeting on Wednesday 11 January 2017, which were agreed and will be published on the SHCA's website.

4. MATTERS ARISING

4.1 Membership update

Reported: as per notes on agenda

Noted: The Secretariat is in active discussions with potential corporate supporters and has also received interest from prospective members.

Agreed: Members to continue to share names of potential clinicians who would be suitable for the clinical advisory board.

5. PROGRESS SINCE THE LAST MEETING

5.1 Letter to the Prime Minister

Reported: as per notes on agenda.

5.2 Meeting with NHS England

Reported: as per notes on agenda.

Reported: Bill Morgan noted that the SHCA is optimistic about building a constructive relationship with NHS England (NHSE) through quarterly meetings with the SHCA's Chair.

Agreed: Members who are interested in participating in the meeting with NHSE on the prioritisation process (which is anticipated to take place in May) should inform the Secretariat.

Agreed: The Secretariat and Chair to raise issues regarding the publication of CRG meeting minutes with John Stewart.

Considered: Members discussed the Rare Disease Advisory Group and utilising parliamentary scrutiny through the Chair and Vice-Chair to seek clarity on its role.

Agreed: The Secretariat to produce a short briefing note on patient voice in decision making processes, ahead of meeting with John Stewart.

5.3 Engagement with the Public Accounts Committee

Reported: as per notes on agenda.

Noted: A letter has been sent to Meg Hillier MP, Chair of the Public Accounts Committee, recommending the Committee hold an inquiry on the impact of STPs on specialised services.

Agreed: The Secretariat would share the briefing sent to Karin Smyth MP with members.

5.4 UK Genetic Disorders Leadership Symposium

Reported: as per notes on agenda.

Agreed: The Secretariat to share the SHCA's presentation slides with members.

5.5 UK Rare Disease Forum

Reported: The Minister of State for Health, Philip Dunne MP announced in the Westminster Hall Debate on Rare Disease Strategy that NHSE would publish an implementation plan for the rare disease strategy by the end of 2017.

The Secretariat has sent an email to the Department of Health to welcome the announcement and has expressed a desire to participate in the design of the implementation strategy.

Reported: There has been discussion around the development of metrics to assess the 51 commitments in the strategy, which will be discussed at the Policy Board meeting in April. The Forum will also create Task and Finish groups to take forward specific projects pertinent to implementation of the Strategy.

Reported: The SHCA has been given early access to the online platform and will be providing feedback before it goes live later this year.

Agreed: The Secretariat will prepare an introductory document with suggestions on what the rare disease strategy implementation plan should contain and will share with members over the next month.

5.6 Scottish Rare Disease Implementation Oversight Group (RDIOG)

Reported: The Secretariat participated in the RDIOG's February meeting where the Group discussed engaging with the Scottish Government's forthcoming Digital Health and Social Care strategy to ensure that it takes account of the needs of patients with rare diseases. The group's main focus is centred on improving data collection and its utilisation for rare diseases.

Agreed: The Secretariat to update members on opportunities to contribute to the RDIOG's work.

POLICY UPDATE

Agreed: Brexit will be included as a standing agenda item for future meetings.

6.1 NHS England / NICE consultation

Reported: The £20 million 'budget impact test' has been retained and widened to apply to Highly Specialised Technologies (HST) products. If a satisfactory deal is not reached, NHS England can request NICE delays or restricts the mandatory funding direction. It was also noted that it is unlikely that biosimilars would be affected as they would be considered as cost saving. If NICE were to make decisions around restrictions it would consult with registered stakeholders but not more widely.

Considered: The impact of the proposals will be considered after three years, however the members debated whether the proposals would last the full length of time.

Considered: Members expressed concern over the restrictions in the response and discussed scrutinising with PQs and through conversations with NHS England.

Noted: NICE has commissioned a report to assess whether current methodologies are appropriate for assessing gene therapies. Members expressed concerns that the evidence considered was limited in scope and therefore the findings on the suitability of NICE's processes may not be valid.

Agreed: The Secretariat will share a note on the evaluation of gene therapies at the next meeting.

Reported: With regards to HST some changes have been accommodated. A weighting system has been introduced whereby the threshold is higher for treatments that offer greater absolute QALY gains, up to £300,000 per QALY.

Considered: Members shared their concerns around the proposals that are due to be implemented from 1 April 2017 and discussed whether it would be possible to seek legal council on the reform to provide more clarity.

Agreed: The Secretariat would send an approved letter to the Chair of the NHS England Board outlining concerns with the proposed reform to the HST processes which were due

to be discussed at the Board meeting on Thursday 30 March 2017. The secretariat would also seek to secure media coverage of members' concerns.

6.2 Sustainability and Transformation Plans (STPs)

Reported: A plan for place-based commissioning of specialised services will be published shortly. NHSE is reviewing the existing reporting and assurance arrangements for specialised commissioning and determining whether these may need to change in light of moving to place-based arrangements.

Considered: Members raised concerns on the implications place-based commissioning could have on patients depending on their location.

6.3 Accelerated Access Review (AAR) and Life Sciences Strategy

Noted: The Government's response to the AAR is expected in April, alongside a life sciences paper. The 'sector deal' is expected to be negotiated after the publication of the AAR.

6.4 NHS England prioritisation process

Reported: as in point 5.2 and agenda.

6.5 Devo Manc

Reported: The Manchester-wide medicines strategy is still under development following the agreement of a memorandum of understanding between the GMCA and the pharmaceutical industry. The memorandum focuses on promoting better access to treatments and a greater collaboration between the NHS and the pharmaceutical industry.

Noted: Andy Burnham's team has been receptive and have shared an invitation for a delegation from the Alliance to meet Andy Burnham and John Rouse, Chief Officer of the Greater Manchester Health and Social Care Partnership in Manchester, should he become Mayor. Dates and timings are yet to be confirmed.

Agreed: The Secretariat will update members on any progress in agreeing arrangements for a delegation to Manchester.

Noted: The Mayoral election is due to take place on Thursday 4 May.

7. PARLIAMENTARY UPDATE

7.1 Health Service Medical Supplies (Costs) Bill

Reported: The Bill has almost finished its passage through Parliament. However, there is disagreement between the House of Commons and the House of Lords on an amendment tabled by Lord Warner aimed at protecting patients' access to NICE approved medicines.

Considered: Members discussed concerns around whether the current amendment would be accepted during a debate on Wednesday 5 April. The Secretariat proposed using the

debate as an opportunity to engage with the Shadow Health team.

7.2 Westminster Hall debate about implementing the UK Strategy for Rare Diseases

Reported: as in point 5.5.

8. GOVERNANCE

Reported: members were asked to approve the updated governance document. The document remains identical to the previous version in all respects, however the details of the current Chair, Vice-Chairs and Secretariat have been updated to reflect changes in 2017.

Agreed: The Governance document was approved by members.