

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE FROM 11.00 – 14.00 ON  
WEDNESDAY 11 OCTOBER 2017 IN THE ARCHBISHOPS' ROOM AT MILLBANK  
HOUSE, MILLBANK, LONDON, SW1P 3JU**

**Present:**

Lord Sharkey – Chair  
Baroness Wheeler – Vice–Chair

Beth McCleverty – Bliss  
Brian Gunson – British Liver Trust  
Chris Sotirelis – UK Thalassaemia Society  
Christopher Hicks – National AIDS trust  
Ciarán Scott – AKU Society  
Claudia Rubin – PHA UK  
Dan Betts – CSL Behring  
David Ryner – CML Support Group  
Emma Barnes – The Children's Trust  
Fiona Loud – Kidney Care UK  
Hannah Chalmers – National Voices  
Jack Feinmann – The British Society for Rheumatology  
Jane Lyons – Cancer52  
Jerome Penn – Pfizer  
John James – Sickle Cell Society  
Kate Downey – Actelion  
Luke Ashton – Merck  
Mary-Beth Peddell – Novartis  
Paul Cox – Sobi  
Paul Pambakian – Shire  
Phil Schwab – AbbVie  
Phillip Anderson – MS Society  
Richard Rogerson – Niemann–Pick UK  
Simon Butler – Anthony Nolan  
Sue Farrington – SRUK

**Secretariat:**

Bill Morgan – SHCA Secretariat  
Ed McIntosh – SHCA Secretariat  
Elizabeth Beck – SHCA Secretariat  
Klark Mullen – SHCA Secretariat

## **1. APOLOGIES**

- Dan Murphy – Gilead
- David Stokes – Cleft Lip and Palate Association
- Iain Clarke – Action Duchenne
- Jill Praver – LPLD Alliance
- Patricia Osbourne – Brittle Bone Society

## **2. MINUTES**

Reported: the minutes of the last meeting on Wednesday 12 July 2017 were agreed and will be published on the SHCA's website.

## **3. MATTERS ARISING**

### **3.1 Membership and Corporate Supporters update**

Reported: Fight for Sight has joined as a new member.

Reported: The SHCA would like to thank its Corporate Supporters for their continued support of the Alliance in 2018.

### **3.2 Vice-Chair update**

Reported: as per notes on agenda.

Reported: The SHCA would like to thank Baroness Redfern for her time spent as Vice-Chair of the Alliance.

Agreed: The Secretariat will inform members once a new Vice-Chair has been confirmed.

### **3.3 Secretariat update**

Reported: as per notes on agenda.

## **4. ACTIVITY UPDATE**

### **4.1 Patient and public involvement – Specialised Commissioning Stakeholder Forum**

Reported: as per notes on agenda.

Agreed: The Secretariat will request more information from NHSE on patient and public involvement. **Done**

Agreed: The Secretariat will request an update from NHSE on the next steps and timelines of the Forum. **Done**

### **4.2 UK Strategy for Rare Diseases**

Reported: as per notes on agenda.

Agreed: The Secretariat will provide a note of the annual conference of the Rare Disease Forum which will take place on 24 November in Birmingham. **30.11.17**

Agreed: The Secretariat will request more information from the Department of Health on the integration of health and social care for specialised services as part of the draft implementation plan. **Done**

#### **4.3 Specialised commissioning reform update – John Stewart and Gareth Arthur meeting**

Reported: as per notes on agenda.

Reported: It was reported that all STPs are to have a “seat at the table” arrangement by May 2018.

Agreed: The Secretariat will circulate the list of the ten commissioning hubs. **25.10.17**

Agreed: The Secretariat will circulate more details regarding the Readiness Criteria document that NHSE recently shared with the Secretariat. **25.10.17**

#### **4.4 Specialised commissioning reform update – Jon Rouse meeting**

Reported: as per notes on agenda.

Agreed: The Secretariat agreed to liaise with the office of Jon Rouse to clarify the scope and frequency of future meetings and will update members at the next all members' quarterly meeting on 10 January, 2018. **Done**

#### **4.5 Access to treatments – Commissioning Support Programme**

Reported: as per notes on agenda.

Agreed: The Secretariat will develop a living document on the CSP and the Prioritisation Process based on members' experience with the programmes. **Ongoing**

Agreed: The Secretariat will seek clarity on aspects of the CSP Programme and the Prioritisation Process including transparency of evidence. **Ongoing**

#### **4.6 Access to treatments – November CPAG meeting**

Reported: as per notes on agenda.

Agreed: The Secretariat will communicate members' concerns over the transparency of the CPAG meeting and seek clarification over the steps NHS England is taking to clarify its reporting and methods of working. **Done**

#### **4.7 Access to treatment – High Cost Drugs List**

Reported: as per notes on agenda.

Agreed: The Secretariat will clarify the nature of the review of the High Cost Drug List with

NHSE. **Done**

#### **4.8 Access to treatment – Scotland and the Montgomery Review**

Reported: as per notes on agenda.

Agreed: The Secretariat will keep a watching brief on the implementation of recommendation 28 on the development of a Scottish Model of Value. **Ongoing**

#### **4.9 Access to treatment – Life Sciences Strategy**

Reported: as per notes on agenda.

Reported: It was reported that the Strategy is due to be published on 30 October.

Agreed: The Secretariat will develop a letter to be sent on behalf of Lord Sharkey, Chair of the SHCA, to Lord O'Shaughnessy in support of the strategy and recalling the importance of implementing its recommendations. This letter will be discussed at the next quarterly all members' meeting on 10 January. **31.10.17**

#### **4.10 Brexit**

Reported: as per notes on agenda.

Agreed: The Secretariat will contact the Department of Health regarding the issue of the import and export of organs in the context of Brexit and update members. **Done**

### **5. KEY ACTIVITY OVER THE LAST QUARTER**

#### **5.1 Developing the SHCA's contribution to policy – UK Strategy for Rare Diseases**

Reported: as per notes on agenda.

#### **5.2 Developing the SHCA's contribution to policy – DevoManc**

Reported: as per notes on agenda.

### **6. LUNCH**

### **7. PROPOSED ACTIVITIES FOR 2018**

#### **7.1 Maintaining an effective Secretariat**

Agreed: The Secretariat will consider organising an external event in 2018 and will provide an option paper for consideration at the next all members' quarterly meeting on 10 January.

**8.1.18**

## **7.2 Securing high quality speakers for our meetings**

Reported: The Secretariat confirmed that Andrew Dillon, Chief Executive of NICE, will be the guest speaker at the next all members' quarterly meeting on 10 January.

Agreed: The Secretariat agreed to consider high profile speakers in Scotland, Wales and Northern Ireland. **Ongoing**

## **7.3 Providing informed commentary**

Reported: as per notes on agenda.

## **7.4 Mobilising politicians**

Reported: as per notes on agenda.

## **8. APPROVAL OF 2018 PLANS AND SECRETARIAT**

Reported: as per notes on agenda.

Noted: Members approved the plans for 2018 and the continuation of the Incisive Health Secretariat.

Agreed: The Secretariat agreed to share timelines for future actions and projects with members, provide further details on the use of the budget for 2018, include communications activity as a standing item on future agendas and ensure that patients are at the heart of all of the SHCA's activity. **Ongoing**