

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE, THURSDAY 4 APRIL 2019  
(11.00 – 14.00) IN COMMITTEE ROOM G, THE HOUSE OF LORDS**

**Present:**

Lord Sharkey - Chair

Baroness Chisholm - Vice-Chair

Allan Muir - Association for Glycogen Storage Disease

Alex Massey - Motor Neurone Disease Association

Anna Evans - Cystic Fibrosis Trust

Bob Stevens - MPS Society

Bradley Price - Anthony Nolan

Chris Sotirelis - Patient representative for thalassaemia

Christopher Hicks - National AIDS Trust

Ciarán Scott - AKU Society

Constantinos Skinitis - Novartis

Dan Betts - CSL Behring

David Ryner - Chronic Myeloid Leukaemia Support Group

Diane Splevings - Shire

Eleonora Lovato - Gilead

Professor Gareth Morgan - The Children's Trust

Graham Coates - BioMarin

Jeff Courtney - The Haemophilia Society

Jerome Penn - Actelion

John James - Sickle Cell Society

Jonathan Kingsley - Muscular Dystrophy UK

Katharine McIntosh - Neurological Alliance

Laura Szutowicz - HAE UK

Len Woodward - aHUS UK

Lindsay Weaver - Climb

Lisa Bashorum - Amicus Therapeutics

Roger Brown - Waldenström's Macroglobulinemia UK

Samantha Barber - Batten Disease Family Association

Steve Bojakowski - Sobi

Sue Farrington - Scleroderma & Raynaud's UK

Tom Harrison - MS Society

**Secretariat:**

Ed McIntosh - SHCA Secretariat

Elizabeth Beck - SHCA Secretariat

Henry Poust - SHCA Secretariat

Maddy Farnworth - SHCA Secretariat

**1. APOLOGIES**

Baroness Wheeler - Vice-Chair

Bill Morgan - SHCA Secretariat

**Specialised Healthcare Alliance**

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[www.shca.info](http://www.shca.info)

Brian Gunson - Liver4life  
Fiona Loud - Kidney Care UK  
Hassan Abu-Bakir - Fight for Sight  
Jane Lyons - Cancer52  
Lesley Kavi - Postural Tachycardia Syndrome UK  
Louise Fish - Tuberous Sclerosis  
Lynne Regent - Anaphylaxis Campaign  
Patricia Osborne - Brittle Bone Society  
Richard Rogerson - Niemann-Pick UK

## **2. MINUTES**

Reported: the minutes of the last meeting on Wednesday 6 February 2019 were agreed and will be published on the SHCA's website. **Done**

## **3. UPDATE ON CORPORATE SUPPORTERS**

Reported: The SHCA would like to welcome Amicus Therapeutics to the Alliance.

## **4. KEY POLICY ISSUES**

### **4.1 NHS Long Term Plan and legislative proposals**

Reported: as per notes on agenda.

Agreed: SHCA Secretariat to follow up with NHS England's senior leadership on the implementation plan for specialised services being developed to move forward with the proposals for integrated planning set out in the NHS Long Term Plan and Operational Planning Guidance. **Ongoing**

### **4.2 NHS review of clinical standards**

Reported: as per notes on agenda.

### **4.3 Prioritisation process**

Reported: as per notes on agenda.

Agreed: Members to feedback to the SHCA on their experiences of producing Current Lived Experience Reports as part of the prioritisation process. **As appropriate**

Agreed: SHCA Secretariat to continue to monitor developments around changes to evidence considered in the prioritisation process (including Current Lived Experience reports) and keep members updated. **As appropriate**

### **4.4 NICE methods and process review**

Reported: as per notes on agenda

#### **4.5 UK Strategy for Rare Diseases**

Reported: as per notes on agenda.

#### **4.6 Devolved nations update**

##### ***Scotland***

Reported: as per notes on agenda.

Agreed: Members to feedback their experiences of the SMC's new ultra-orphan pathway to the Secretariat. **As appropriate**

##### ***Wales***

Agreed: SHCA Secretariat to enquire into the AWMSG's position on the upcoming NICE methods and process review. **18.04.19**

##### ***Northern Ireland***

Agreed: SHCA Secretariat to write to Richard Pengelly, Permanent Secretary of the Department of Health in Northern Ireland, to follow up on the implementation of the new IFR process. **18.04.19**

#### **4.7 Brexit**

Reported: the SHCA Secretariat provided an update on ongoing developments related to Brexit.

#### **4.8 Clinical Priorities Advisory Group vacancies**

Reported: the SHCA Secretariat provided an update on NHS England's recruitment process for new Patient and Public Voice (PPV) members to be part of its Clinical Reference Groups (CRGs).

Agreed: SHCA Secretariat to write to John Stewart, Director of Specialised Commissioning at NHS England, to highlight concerns on variation in the number of PPV members across CRGs, and enquire as to why the changes to membership were not consulted on more widely. **12.04.19**

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

#### **5.1 2019 member survey**

Reported: as per notes on agenda.

Agreed: SHCA Secretariat to circulate an updated version of the 2019 member survey for comment. **Done**

Agreed: Members to provide feedback on the questions before the survey goes live on 1 May. **25.04.19**

## **5.2 Letter to Secretary of State for Health and Social Care on access to treatment**

Reported: as per notes on agenda.

## **5.3 Baroness Blackwood on Brexit**

Reported: Baroness Blackwood has agreed to speak at the next SHCA quarterly meeting on 5 June 2019.

## **6. PROPOSED ACTIVITY OVER NEXT QUARTER**

### ***6.1 Exploring the growing differences in access policy across the UK***

Reported: as per notes on agenda.

Agreed: SHCA Secretariat to begin the development of a report on growing differences in access policy across the UK and its impact on patients, specifically exploring what processes could work most effectively across the UK. **Ongoing**

### ***6.2 Developing SHCA positions on health technology appraisal reform in England***

Reported: as per notes on agenda.

Agreed: SHCA Secretariat to gather members' views on NICE reform before an external paper is developed ahead of the NICE consultation on its methods and services. As part of the paper's development, SHCA Secretariat to liaise with the Genetic Alliance to ensure its position is aligned. **Ongoing**

## **7. LUNCH**

## **8. GUEST SPEAKER**

Reported: as per notes on agenda.

## **9. ANY OTHER BUSINESS**

Reported: date of next meeting confirmed as Wednesday 5 June 2019.