

Specialised Healthcare Alliance

FOR EVERYONE WITH RARE AND COMPLEX CONDITIONS

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE FROM 12.15 – 13.15 ON
TUESDAY 28 NOVEMBER 2017 AT THE DEPARTMENT OF HEALTH, 39 VICTORIA
STREET, LONDON, SW1H 0EU**

Present:

Baroness Wheeler – Vice-Chair

Brian Gunson – British Liver Trust

Beth McCleverty – Bliss

Cassandra Staines – Anthony Nolan

Chris Sotirelis – UK Thalassaemia Society

Christopher Hicks – National AIDS trust

Claudia Rubin – PHA UK

David Ryner – CML Support Group

David Stokes – CLAPA

Daniel Burden – Spinal Injuries Association

Edward Nickell – Specialist Orthopaedic Alliance

Emma Barnes – The Children's Trust

Hannah Chalmers – National Voices

Iain Clarke – Action Duchenne

Jack Doughty – MS Society

Jack Feinmann – The British Society for Rheumatology

Jane Lyons – Cancer52

John James – Sickle Cell Society

Richard Rogerson – Niemann–Pick UK

Secretariat:

Ed McIntosh – SHCA Secretariat

1. APOLOGIES

- Jane Lyons - Cancer52

2. MEETING WITH LORD O'SHAUGHNESSY

Reported: Baroness Wheeler provided an introduction to the SHCA, including an overview of its history, membership and priorities.

Reported: Lord O'Shaughnessy welcomed the opportunity to meet with the SHCA and outlined the Department of Health's role in overseeing the delivery of specialised services by NHS England. He highlighted the significant level of investment in specialised services and noted the challenges created by the breadth of issues.

The Minister invited questions from the members present, with issues raised including:

- The complex structure of commissioning of services affecting patients living with rare and complex conditions, which can result in fragmentation in services for these conditions
- The importance of the Government and NHS England utilising the resources and expertise of the voluntary sector when making decisions about patients with rare and complex conditions
- The need for NHS England to focus on patients rather than structures when considering reforms to specialised commissioning
- The challenges that have been experienced in engaging with NICE's Commissioning Support Programme calls to evidence, related to the short timelines for responses and the nature of the evidence that NICE will accept
- The challenges that have been experienced in securing patient and public involvement in NHS England's specialised commissioning decision making processes
- The difficulty that small charities face in finding resources to commission research on the experience of patients which could help to inform and improve NHS decision making

Noted: Lord O'Shaughnessy noted that the Government had signaled its intention to speed up the adoption of cost-effective treatments for rare and complex conditions through the Accelerated Access Review and to improve the research environment through the Sector Deal. He highlighted the importance of the Life Sciences Industrial Strategy in signaling a change in approach and noted the Sector Deal would build on recommendations related to advanced manufacturing.

The Minister informed the group that he would be discussing patient involvement in decision making with NHS England and would reflect on the issue of research funding for small charities.