

ALL PARTY PARLIAMENTARY GROUP ON RARE, GENETIC AND UNDIAGNOSED CONDITIONS



Rare Disease Day reception and Annual
General Meeting: minutes

Date: **27 February 2019**

Venue: **Terrace Pavilion, Houses of Parliament**

Parliamentarians

Catherine West MP
Rt Hon Baroness Neville-Jones
Alex Sobel MP
Bambos Charalambous MP
Baroness Hollins
Baroness Masham of Ilton
David Duguid MP
David Simpson MP
Lloyd Russell-Moyle MP
Lord Rogan
Mark Pritchard MP
Neil O'Brien MP
Pauline Latham OBE MP
Rehman Chishti MP
Rt Hon George Howarth MP
Sharon Hodgson MP
Sir David Amess MP
Stephen Kerr MP
Steve Pound MP
Tan Dhesi MP
Virendra Sharma MP
Peter Dowd MP

Guest Speakers

Dr Jayne Spink, Genetic Alliance UK
Baroness Nicola Blackwood
Mishal Dattani

1. Welcome from Catherine West MP

Annual General Meeting – election of the officers.

Election of chair: Catherine West MP.

The election of the chair was seconded by Alex Sobel MP, Bambos Charalambous MP and Lloyd Russell-Moyle MP.

Election of vice chairs: Rt Hon Baroness Neville-Jones, Lord Patel, Lord Turnberg and Rt Hon Dame Cheryl Gillan MP.

Genetic Alliance UK
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www.geneticalliance.org.uk
Registered charity numbers: 1114195 and SC039299
Registered company number: 05772999

Election of officers: Alex Sobel MP, Rt Hon Norman Lamb MP.

Catherine West MP opened up the Rare Disease Day reception by welcoming attendees and highlighted common challenges affecting rare disease patients such as getting a diagnosis, accessing accurate information and support, and the emotional impact of living with a rare condition.

2. **Dr Jayne Spink, Chief Executive, Genetic Alliance UK, and Chair of Rare Disease UK**

Dr Jayne Spink noted that the UK Strategy for Rare Diseases is nearing its deadline of 2020 but there is still much work to be done to improve the experience and treatment of rare disease patients. Since its publication in 2013 many bodies and initiatives in the Strategy have changed or ceased to exist. Rare Disease UK is calling for a review and refresh of the Strategy before 2020 to ensure progress and momentum is not lost.

Dr Jayne Spink presented Baroness Blackwood, the minister with responsibility for rare diseases, with an [open letter](#) signed by over 100 patient organisations calling for a refresh and review of the UK Strategy for Rare Diseases.

3. **Screening of ‘[Ian’s rare reality](#)’, a patient experience video**

4. **Baroness Nicola Blackwood, Parliamentary Under Secretary of State at the Department of Health and Social Care**

Baroness Blackwood informed attendees of the publication of an [update from the Department of Health and Social Care](#), outlining the progress towards delivering the UK Strategy for Rare Diseases. She also reaffirmed the Government’s commitment to European Reference Networks and stated that there would be a rare disease ‘framework’ in place post 2020.

The Minister has asked NHS England to implement a rare disease ‘insert’ which will ensure that: there is a person responsible for co-ordinating the care of some patients with rare diseases (those with access to specialised services); every patient with a rare disease will have an ‘alert card’, including information about their condition, treatment regime and contact details for the individual expert involved in their care; and, every paediatric patient has an active transition to an appropriate adult service, even if that adult service is not the commissioning responsibility of NHS England.

Finally, Baroness Blackwood also launched the development of a [National Genomic Healthcare Strategy](#) aiming to ensure rare disease patients receive a faster and more accurate diagnosis, as well as providing access to personalised treatment and care.

5. **Mishal Dattani, patient speaker**

Mishal shared his experience of living with Budd-Chiari syndrome, a blood related liver condition affecting approximately one in a million people. In addition to outlining his diagnostic odyssey Mishal outlined the challenges he has faced in living with a rare condition, such as managing his care with regular blood tests, appointments and visits to clinics, in addition to holding down a job.

6. **Close**