**Minutes of the Annual General Meeting of the All-Party Parliamentary Group on 22q11 Syndrome**

**Date:** Wednesday 11th May 20

**Time:** 10:30 – 12:30

**Location:** Room W3, Westminster Hall

**Attendees**

* Suzanne Webb MP
* David Duguid MP
* Flick Drummond MP
* Jack Lopresti MP
* Jerome Mayhew MP
* Lord Farmer
* Julie Wooton – Chair of Max Appeal
* Martin Kennedy – Trustee of Max Appeal
* Claire Hennessey – Development Officer of Max Appeal
* Mandy Sanderson – Interim Learning Disabilities and Autism Programme Lead at NHS England and NHS Improvement - London Region Specialised Commissioning
* Dr Imke Myers-Peterson – General Paediatric Consultant at Great Ormond Street Hospital
* Virtual Speaker – Dr Samantha Leonard from Natera
* Marcus Boyle – Parliamentary Researcher for Suzanne Webb MP
* Luke Bennett – Parliamentary Staffer for Jack Lopresti MP

1. Suzanne Webb MP declared the meeting open and quorate. She listed apologies for the meeting and welcomed attendees.
2. Attendees introduced themselves and their roles.
3. Suzanne Webb MP opened voting proceedings for officers of the APPG and the following were duly elected:

* Chair – Suzanne Webb MP (Conservative)
* Officer – Alex Sobel MP (Labour)
* Officer – David Duguid MP (Conservative)
* Officer – Jack Lopresti MP Conservative)
* Officer – Lord Farmer (Conservative)

1. Suzanne Webb MP led a discussion on the progress the APPG and its secretariat Max Appeal have made since the last meeting of the group. Julie Wooton and Claire Hennessey gave the meeting an update on the work of Max Appeal, including the success of the Consensus Document and the work that is being carried out to update the document. Julie then spoke about the success Max Appeal has had in reaching out to people with 22q11 across the UK, with the charity now having over 2000 members with 22q11.
2. Suzanne Webb MP then introduced the four speakers.
3. Martin Kennedy spoke about the lack of support given by the education system to children with 22q11 during and after they leave school. He advocated for apprenticeships as a vocational means to support people with 22q11 into jobs. He highlighted the challenge the Apprenticeship Levy poses to disadvantaged children. Many large employers do not spend their levy allowance. He suggested that this surplus could be used as an incentive for employers to hire apprentices with 22q11.
4. Mandy Sanderson spoke about new-born screening and genetic testing. She noted that they had put in an application for 22q11 to be included in the Newborn Screening Programme in 2018 yet it was rejected. She spoke about the work that is being done to re-apply for the Programme, including greater research and political engagement.
5. Imke Myers-Paterson spoke about the work of the 22q11 Deletion Syndrome Clinic and Great Ormond Street Hospital (GOSH), which is designed to ensure every child and young person with 22q11 Deletion syndrome receives appropriate care and long term follow up. Although progress has been made in the past five years, she stated that funding, capacity, and a lack of support from hospital executives had been a challenge for the clinic.
6. [Natera speaker] spoke about pre-natal screening. She highlighted how 22q11 is relatively frequent and how non-invasive pre-natal tests can now screen for 22q11. She spoke about how early testing allows for effective interventions and allows for parents to begin accessing support early on.
7. There was then a discussion on the need for 22q11 and other rare genetic conditions to get legal parity, similar to how the Down Syndrome Act achieved this for Down Syndrome.
8. Suzanne Webb MP then led a discussion of the aims of the APPG for the forthcoming year. The following actions were agreed.

* The parliamentarians present would look at tabling oral questions and entering the Private Members’ Ballot to help raise awareness of 22q11 and increase political engagement.
* Max Appeal to contact Alex Burghart MP, Minister for Apprenticeships and Skills, to follow-up on Martin’s concerns and proposals about apprenticeships for young people with 22q11.
* Max Appeal to encourage their membership to contact their MPs to increase parliamentary engagement.
* The APPG to look at organising an autumn reception in November for parliamentarians and members of Max Appeal. Date – TBD.

1. No further matters were raised and Suzanne Webb MP declared the meeting closed.