22q11 APPG AGM 090523

Minutes

**Attendees**

* David Duguid MP
* Lord Farmer
* Rt Hon Sir Robert Goodwill MP
* James Morris MP
* Sir Peter Bottomley MP
* Paul Howell MP
* Claire Hennessey (Max Appeal)
* Carla Attwood (Max Appeal)
* Mandy Sanderson (Max Appeal)

**Apologies**

* Baroness Eaton DBE DL
* Jack Lopresti MP
* Marion Fellows MP
* Alex Sobel MP
* Julie Wooton (Max Appeal)
* Suzanne Webb MP

**Voting for Officers**

* David Duguid MP – Chair
* Alex Sobel MP – Officer
* Lord Farmer – Officer
* Jack Lopresti MP – Officer
* Baroness Eaton DBE DL - Officer

1.     David Duguid MP declared the meeting open and quorate. He listed apologies for the meeting and welcomed attendees. He further advised that Suzanne Webb MP was stepping down as Chair of the APPG and invited him to stand in for her at this meeting, pending election of new Chair and officers.

2.     Attendees introduced themselves and their roles

3.     David Duguid MP opened voting proceedings for Officers of the APPG. The following were elected:

* + 1. Chair – David Duguid MP (Conservative)
		2. Officer – Alex Sobel MP (Labour)
		3. Officer – Baroness Eaton DBE DL (Conservative)
		4. Officer – Jack Lopresti MP Conservative)
		5. Officer – Lord Farmer (Conservative)

4.     Mandy Sanderson from Max Appeal spoke first, providing a history of Max Appeal and the 22q11 APPG. Mandy discussed the progress made from raising awareness of the condition. Mandy also advised that not much progress had been made by the APPG following the conclusion of the Covid-19 pandemic. Issues regarding employment opportunities and support, especially when someone with 22q11 transfers from childhood social care into adult social care were also discussed and highlighted by Mandy.

**ACTION**: *Mandy to transcribe her excellent opening summary and share with Parliamentarian members of APPG.*

5.     Carla Attwood discussed the APPG’s work with other charities and the wider care sphere.

6.     Group discussed the advances of diagnostic technology and how that can assist in the care of people with 22q11 syndrome.

7.     Group then discussed the Down Syndrome Act 2022. The members agreed that they were disappointed that 22q11 was not significantly considered in the Guidance as was promised – as well as the lack of inclusion of reference to other genetic conditions as was stated by the DHSC.

8.     **ACTION**: *David Duguid MP agreed to take up this point with the Department.*

9.     The group further discussed the forthcoming Genomics England pilot study of testing babies at birth, giving the opportunity to speed up the diagnosis of about 200 rare genetic diseases and ensure faster access to treatment. Attendees hope 22q11 Syndromes will be included.

**ACTION**: *Claire to provided David with appropriate wording of question for David to then seek response from DHSC*

10.  Lord Farmer spoke about his work in the House of Lords and that he will put in for a debate in the Chamber. Since the meeting, Lord Farmer’s office have confirmed that a Short Debate in the House of Lords has been requested and that this topic was currently third on the reserve list.

**ACTION**: *David Duguid to look into similar Parliamentary mechanisms in Commons (e.g. Adjournment Debate, WM Hall Debate, WPQs etc.)*

**ACTION**: *Max Appeal to provide ‘script’ for questions, briefing material etc*.

11.  David Duguid MP then led a discussion of the aims of the APPG for the forthcoming year. The following objectives were agreed:

* The ultimate aim as always is to get early detection in newborns by getting 22q added to the standard newborn blood screen (heel prick) test.
* Get 22q included in the Genomics England Pilot Study
* Get 22q and other lifelong genetic conditions added to guidance prompted by Down Syndrome Act 2022
* Raise awareness – through various means, PQs, debates, (in both Houses) Press Releases etc. and seek new members. Autumn reception to tie in with 22 Nov

**ACTION**: *David Duguid MP to investigate possible engagement options with the Scottish Parliament in Holyrood*

12.  No further matters were raised, and David Duguid MP declared the meeting closed.