**Minutes: APPG 22q11 Syndrome AGM – 20 March 2024**

**Attendees**

* David Duguid MP (DD)
* Julie Wootton (APPG Secretariat and Max Appeal) (JW)
* Paul Wootton (Max Appeal) (PW)
* Max Appeal member
* Lord Farmer (LF)
* Samantha Callan (Lord Farmer’s Office) (SC)
* Natalie Elphicke MP (NE)
* Lord Borwick (LB)
* Chris Green MP (CG)
* Liz Twist MP (LT)

**Apologies**

* Baroness Eaton DBE DL
* Alex Sobel MP (AS)
* Ian Levy MP
* Lord Stone of Blackheath
* Nickie Aiken MP
* Baroness Cox
* Lord Lipsey
* Baroness Hollins
* Baroness Finlay
* James Grundy MP
* Jack Lopresti MP
1. **Attendees introduced themselves.**
2. **Review of 2023 Activities**

Parliamentary Reception on 13 December:

We had hoped to launch the National Consensus Document but it is still in formation. However, we did bring together international leaders and the Minister responsible for newborn screening.

20 week pre-natal screening was also mentioned but this requires a completely different ethical perspective.

We continue to work with other APPGs e.g Rare Diseases APPG chaired by Liz Twist. She mentioned Rare Disease Day on 29th February 2024 and the issuing of alert cards for some conditions that need specialist help.

We are also part of the Newborn Screening Coalition.

1. **APPG administration**

The issue was raised as to whether a separate account is needed for the APPG.

DD said Jonny would investigate if APPG needs separate account.

We also need to set a reporting point in the year?

Expenditure and income from Max Appeal – not the APPG - is around £15k per annum.

1. **APPG Aims for this Parliament**

The meeting was quorate and officers were appointed and registered on the APPG form. The following Members were elected as officers:

* David Duguid (Con) – Chairman
* Lord Farmer (Con) – Officer
* Alex Sobel (Lab) – Officer
* Baroness Eaton (Con) - Officer

It was agreed that it was worthwhile to monitor other events in Parliament eg of APPGs on similar agendas, as mentioned earlier.

LF mentioned asking oral and written questions. Max Appeal sad they would help with ideas for WQs re:

* Newborn screening conditions
* Specialised commissioning

DD proposed Adjournment debate and/or Westminster Hall debate.

SS suggested we try to get expert speakers to address specific subjects at APPG meetings. One suggestion was to invite someone from the National Screening Committee.

Alternatively the APPG could book the Jubilee Room for an awareness raising even to which MPs and peers could be invited.

1. **Short presentation on Transitions from a member of Max Appeal**

L (*identity shortened*) is now aged 19 – diagnosis of 22q at 4 years. She developed platelets condition, immunology, anxiety, lymph nodes.

However, despite this complex set of conditions, there is very little medical support when transitioning out of Paediatrics into Adult care.

It was mentioned that following treatment in Evelina Children’s Hospital and Great Ormond St Hospital, patients who are young people are cast somewhat ‘into the abyss’ after they are required to move on age-wise.

Speech and language services do little for adults.

There are now more known 22q cases requiring access into adult services through routes other than cardiac but it is very hard to get into congenital disorders services.

**Date of next meeting** – [Proposed for 10July]

**Action**

* JT secures meeting room for Wednesday 10 July
* JT will look into the reporting point and whether it needs to be set ourselves.
* JW and Max Appeal will draft WPQ’s to suggest to the APPG
* JT and DD will discuss lodging an Adjournment/Westminster Hall Debate
* DD and JW discuss inviting speakers to future meetings or booking the Jubilee Room to hold an event