

AGENDA

All Party Parliamentary Group for 22q11 Syndrome

Committee Room 7, House of Commons,

23rd June 2015

1. Welcome and Introduction by Jack Lopresti MP
2. Apologies
3. Election of Officers
4. Living with a child with 22q11 Syndrome by Julie Wootton (5 mins)
5. APPG Aims for this Parliament
6. Date of next meeting
7. Any other business

Draft Minutes of the Annual General Meeting of the All Party Parliamentary Group for 22q11 Syndrome

Committee Room 7, House of Commons,

23rd June 2015

In attendance

Jack Lopresti MP. Lady Silvia Herman MP. Stephen Hepburn MP. Nigel Adams MP. Sheryll Murray MP. Rosie Cooper MP. David Anderson MP. Charlotte Leslie MP. Oliver Colville MP. Mark Durkan MP. Gavin Robinson MP.

1. Jack Lopresti MP declared the meeting open and quorate. He thanked everyone for attending the AGM for the 22q11 deletion syndrome and introduced those present, he then outlined the purpose of the APPG and this meeting.
2. The following officers of the APPG were duly proposed and elected:

Chair	Jack Lopresti MP - Conservative
Treasurer	Lady Sylvia Herman MP - Ulster Unionist
Vice-chairs	Stephen Hepburn MP - Labour
	Nigel Adams MP - Conservative
	Sheryll Murray MP - Conservative
	Rosie Cooper MP – Labour
3. Julie Wootton the chair of Max Appeal (the charity acting as secretariat to the APPG) gave a brief outline of the issues being faced by people who have the condition, or child or family member who have 22q11DS. It was agreed that the condition affected all aspects of family life and was something that should be brought to the attention of MPs so they could better serve the needs of their constituents.

4. A good debate ensued concerning the APPG Aims for this Parliament. It was agreed that the long term objective was to bring a substantive report to the house concerning the effects of the condition and the ramifications that had for health, education and social care providers in terms of known costs and efficiencies of having co-ordinated care and support. The tests to diagnose the condition, perceptions of those with the condition to society, and the estimated prevalence of the condition were also discussed.

5. The agreed actions were:
 - Max Appeal to:
 - organise an academic to attend the next meeting to inform members of a research project.
 - Commence work to produce the long term report on researching costs and multiple appointment costs as opposed to a specialist clinic.
 - Supply feedback from Great Ormond Street on their costs of running the specialist clinic.
 - Report back on the findings of the Great Ormond Street study on mental health issues in young people with 22q11DS.
 - Encourage Max Appeal members whose MP did not attend this meeting to write expressing disappointment.
 - Jack Lopresti MP to:
 - Propose a Parliamentary question
 - Call for an adjournment debate/debate in Westminster Hall
 - Selina Short to:
 - Provide the secretariat with the new rules for APPG

6. Date of next meeting
TBA – but before Christmas

7. No matters were raised under any other business and Jack Lopresti MP declared the meeting closed.