

Initial Meeting

19th April 2014

At Jack Lopresti MP's local office

Present: Claire Hennessey, Carla Attwood, Julie Wootton, Paul Wootton, Selina Short, Dr Alex Habel

Proceedings:

Jack opened the meeting with a brief history about how the meeting had been organised; Carla had recently contacted him because he was her MP and after talking to him about her daughter's condition Jack was very keen to form the All-Part Parliamentary Group and so he agreed to the meeting with his Selina, his Office Manager, at his local office in Bristol.

The purpose of the meeting was to establish the basis of the APPG and set the goals in place for forming the APPG.

Max Appeal had drawn up a briefing document (Appendix 1) that was presented to Jack at the meeting. He and his office manager Selina, were happy that the document had been prepared as it covered most of the areas of preliminary concern.

The discussions then moved on the how to move things forward. Max Appeal would act as the secretariat to the APPG and supply the necessary funding to run it. Max Appeal would for a sub-committee and the suggested the Next Steps (Appendix 2).

The final area discussed was how to recruit MPs and Lords to join the APPG. It was decided that Selina would write (Appendix 3) to all the MPs, Jack would discuss the APPG at all opportunities and Max Appeal would encourage its membership to write to their MP using the suggested template (Appendix 4) to join the group. The other stakeholder groups in the UK were identified as being 22q Northern Ireland and 22 Crew and these groups would also be asked to similarly contact their members.

It was agreed that Selina would try to schedule the first meeting of the APPG to vote in the officers of the group as soon as possible.

Jack closed the meeting.

Appendix 1

22q11 syndrome All-Party Parliamentary Group

Briefing Document

Group Officers

Chair: Jack Lopresti MP (Registered Contact)
Vice Chair: Nigel Adams MP

Group's Secretariat

Max Appeal - Registered Charity Number 1088432. Max Appeal will adhere to the APPG Rules for charities to act as Group Secretariat.

Max Appeal Sub-Committee

Julie Wootton	-	Chair - Max Appeal, chair of trustees
Claire Hennessey	-	Vice Chair - Max Appeal, development officer
Paul Wootton	-	Treasurer - Max Appeal, treasurer
Dr Alex Habel	-	Medical Expert
Carla Attwood	-	Administrator/Secretary

The Sub-Committee:

- will meet (either in person or via tele conference) to agree the dates of meetings and the AGM in accordance with the APPG Rules.
- will facilitate appropriate subjects for meeting discussions and speakers where necessary.
- will supply the Administrator/Secretary with any such materials that it can and are required to fulfil that role.
- members will not act unitarily.

The Administrator/Secretary will:

- be the first point of contact with the Group's Members.
- discuss with the Vice Chair and the Group Chair as to the appropriateness of dates and proposed meeting discussion topics.
- bear in mind the pertinent dates of sitting and debates within the Houses.
- ensure that both the Group Chair and the Sub-Committee are aware of and adhere to the APG rules.
- Keep good accurate records of correspondence, meetings and discussions for circulation to the Sub-Committee and Group Members as appropriate.

The Vice Chair:

- will be the first point of contact with the Administrator/Secretary.

Purpose of the 22qDS APG

To inform and educate parliamentarians about 22q11.2 deletion/duplication syndrome (22q11DS), the commonest of the rare genetic disorders and cause of schizophrenia and other mental health problems, and the second commonest cause of congenital heart disease; to encourage and promote work undertaken to improve its diagnosis and treatment; and to inform parliamentarians about the work of Max Appeal and issues concerning 22q11DS.

22q11DS All-Party Parliamentary Group

Max Appeal Sub-Committee

Next Steps

To establish the APPG

- Call to all members to approach their MP with the attached suggested letter.
- Draw up a list of warm MPs, those who attended the launch of the consensus document and those who sit on APPGs of a similar or compatible subject.

APPG Meetings

- Consider the “bookshelf” ie the list of proposed potential meeting subjects by:
 - Reviewing the surveymonkey/questionnaire, both questions and responses as they come in.
 - Supply potential (good) speakers for those subjects (do NOT invite anyone!)
 - Monitor the social and political press to gauge up-coming ‘sexy’ subjects that will engage MPs/lords.

Appendix 3

Letter from Jack Lopresti MP to all members of both Houses.

Date:

Dear

Join an All-Party Parliamentary Group for 22q11 syndrome

Please join the All-Party Parliamentary Group for 22q11 syndrome because awareness of this this common lifelong genetic condition and awareness needs to be firmly on the agenda of decision makers and influencers in the UK.

22q11 syndrome probably affects upwards of 35,000 people in the UK but is still widely unrecognised; many people go undiagnosed and most families struggle to access appropriate care from services including medical, educational, social and securing appropriate employment.

Last year the 22q11 syndrome charity, Max Appeal, launched the UK's first "National Consensus Document for 22q11DS" at the House of Commons which was enthusiastically embraced by professionals and families both within the UK and internationally.

You can find out about 22q11 syndrome and the people it affects by visiting the Max Appeal website at www.maxappeal.org.uk or scanning this qr code:



Please can you tell me if you will join the 22q11 syndrome APPG .

Yours sincerely,

Appendix 4

Letter from Max Appeal, 22q Northern Ireland and 22 Crew members to their MP.

Dear

Join an All-Party Parliamentary Group for 22q11 syndrome

I live in your constituency and I would ask you to support and join an All-Party Parliamentary Group for 22q11 syndrome because a close member of my family is affected by this common lifelong genetic condition and awareness needs to be firmly on the agenda of decision makers and influencers in the UK.

22q11 syndrome probably affects upwards of 35,000 people in the UK but is still widely unrecognised; many people go undiagnosed and most families struggle to access appropriate care from services including medical, educational, social and securing appropriate employment.

(Please insert here details about your family member and how the condition affects them if you wish).

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Please can you tell me if you will join the APPG being set up by Jack Lopresti MP and I will write to Max Appeal.

Yours sincerely,