



News release: 2 December 2014

MP's join forces to support children with 22q11 Syndrome

***All Party Parliamentary Group
set up today for Bristol and Stourbridge based children's charity***

Today (2 December 2014) Jack Lopresti MP chaired the first meeting to set up an All Party Parliamentary Group [APPG] for Bristol-based Max Appeal. The charity supports those affected by 22q11 Syndrome - a complex condition that is often undiagnosed and leads to lifelong struggles for those affected.

Jack has set up the APPG to raise awareness of this medical condition after meeting one of his constituents who has a daughter with the condition. Nigel Adams MP is the Vice Chair and Margot James MP – a long term supporter of Max Appeal – is Treasurer.

These conditions affect health and quality of life from birth through infancy and childhood into adult life with over 180 physical, functional and psychological associations reported. The complexity of 22q11 frequently leads to clinical confusion and a delay in diagnosis often by years.

At the first meeting parents gave their personal experience living with a children and young adults with 22q11 Syndrome. Dr Alex Habel, retired Consultant Paediatrician Great Ormond Street Hospital, discussed how new genetic technology is helping identify those with 22q11 syndrome, both deletion and duplication.

He says "It is the key to improving these individual's lives by early and anticipatory delivery of care. From conception onwards it affects many body systems, including the heart, palate, immune system, behaviours and mental health. Care is therefore best provided by a multidisciplinary team throughout the life cycle. Education about early recognition of 22q11 syndrome should extend to all

professional disciplines who specialise in delivery of health and psychological services, and education, to children”.

Jack Lopresti MP says; ‘I set up this APPG to raise awareness about this syndrome that is estimated to affect up to 35,000 people in the UK. Currently the detection rate is very low which means many people are not getting the help they need. I am delighted that so many of my colleagues have joined this APPG.’

Julie Wootton, chair of trustees, Max Appeal, says:

“We are delighted to be launching this APPG and are incredibly grateful to Jack Lopresti MP and the MP’s putting their weight behind it. We hope that this will help to raise both awareness and understanding of the needs of these families, their children and adults living with the condition.”

- Ends -

Further information:

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www.maxappeal.co.uk

Notes to Editors

1. Case studies are available for interview, please call the numbers above to make arrangements.
2. Max Appeal is a small national charity, run almost exclusively by a group of dedicated volunteers backed up with a knowledgeable panel of medical professionals. The charity was inspired by Max who sadly had a short life. Today, Max Appeal is a charity with a vibrant life of its own. The charity’s mission is to ensure that every person with 22q11.2 deletion lives an independent and prosperous a life as possible

