My name and address:

MPs name:

MPs address:

Date: Monday 5 January 2015

Dear

**ALL-PARTY PARLIAMENTARY GROUP FOR 22Q AND SUPPORT THE 22Q CLINIC BUSINESS CASE**

I live in your constituency and I would like to ask you to support and join an All-Party Parliamentary Group for 22q11 deletion syndrome because someone close to me is affected by this common lifelong genetic condition and I believe awareness needs to be firmly on the agenda of decision makers and influencers both here in Northern Ireland and in the UK. Health Minister Jim Wells has been speaking with Gillian Cassidy from 22q11 Northern Ireland in an attempt to establish a 22q clinic for those living with 22q in Northern Ireland. 22q probably affects upwards of 35,000 people in the UK (it is the second most common genetic condition after Down’s syndrome) but is still widely unrecognised and currently falls under the Rare Disease umbrella as so many people go undiagnosed. Most families affected by 22q struggle to access appropriate care from services including medical, educational, social and employment.

On 2 December 2014 Gillian Cassidy represented 22q11 Northern Ireland at the first Inaugural Meeting of the APPG for 22q in Westminster hosted by Jack Lopresti MP with no interest by my local constituency leader or disappointingly any other Northern Irish Member of Parliament. I personally felt I would help her in this quest and write to you myself and ask for your support. You can find out about 22q11 syndrome and the people it affects by visiting the Max Appeal website at [www.maxappeal.org.uk](http://www.maxappeal.org.uk), or follow the local support group on Facebook (22q11 Northern Ireland) or Twitter (@22q11\_NI). There is a proposed second 22q APPG meeting due mid-late January and I was wondering if you could contact Gillian Cassidy on 07743554114, email gillian.cassidy@gmail.com or write to 22q11 Northern Ireland, 89 Donaghadee Road, Bangor, BT20 4NJ and show your support by joining this group. I would really appreciate if you could respond and let me know if you can lend your support to this group.

Also, locally Gillian and Tabib Dabir (a geneticist from the Belfast City Hospital) are currently writing a business case for a 22q clinic for those already diagnosed under the Draft Northern Ireland Implementation Plan for Rare Diseases consultation period which is due to be submitted to the Health Minister Jim Wells on 19 January 2015. Last year the English based 22q 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. This document is also a care plan protocol which can be implemented here in Northern Ireland. Your support in creating this 22q clinic will not only save money within the health care system in Northern Ireland through a ‘work smarter’ initiative but change the lives of those living with this syndrome. The Max Appeal hope to use this 22q clinic as a model to be implemented across the UK and then further afield throughout Europe and beyond with Northern Ireland being the ground breaking forerunners in this area. If you could please contact the Health Minister Jim Wells and encourage this 22q clinic I would be most grateful.

I look forward to our future correspondence.

Yours sincerely,

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| 1 - Please choose the Member of Parliament who represents your area, insert their name on the top left hand side of the letter |  |  |
| 2 - Insert your own name on the top right hand side of the letter  |  |  |
| 3- Sign the letter at the bottom of the page with your own name |  |  |
| 4 - Write your MP's address on the stamped envelope provided and pop it in the letterbox! |  |  |
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