**AGENDA**

**All Party Parliamentary Group for 22q11 Syndrome**

**Room B, One Parliament Street, House of Commons**

2nd February 2016

1. Welcome and Introduction by Jack Lopresti MP
2. Apologies  (Nigel Adams)
3. Dr Clodagh Murphy from Great Ormond Street Hospital (GOSH) and the Maudsley Hospital – Mental Health Issues
4. APPG Future Programme
5. Date of next meeting – 8th March 2016
6. Any other business  - None

**Draft Minutes of the All Party Parliamentary Group for 22q11 Syndrome**

**Committee Room 17, House of Commons,**

**In attendance**

Jack Lopresti MP. Lady Silvia Herman MP. Dr Clodagh Murphy, Dr Alex Habel.

1. Welcome and introduction by Jack Lopresti MP.
2. Apologies – Nigel Adams
3. Speaker – Dr Clodagh Murphy from Great Ormond Street Hospital (GOSH) and the Maudsley Hospital – Mental Health Issues

Dr Murphy introduced herself and her background, primarily in child psychology but is working currently in Adult Services.

Whilst there are different ways that children and young people are affected by 22q11 Syndrome, her focus is the brain, commonly because when there are no obvious physical problems reported, the brain is very much overlooked or unreported.

Her findings have shown a very high risk of mental health issues as a result of 22q11 Syndrome, 30-50% of young people have suffered mental health issues, and are quietly missed where there are no visible affects, physically. When mental health issues are overlooked this can have a huge impact on them.

Studies have shown that 4 boys to 1 girl suffer with ADHD, yet girls with 22q11 Syndrome, are equally as likely as boys, which is why it is so important that girls are screened, particularly as girls and boys of a similar age may behave so differently, girls are likely to be inattentive, sit quietly, therefore overlooked.

In teenagers, the most common effects are Generalised Anxiety Disorder (GAD), Mood Swings, Obsessive Compulsive Disorder (OCD), Severe Anxiety, which again can be dismissed as common behaviour of that age group. All these are treatable but services are not in place to assist.

Most concerning are those suffering with psychosis:

Around 1% of the general population (those without 22q11 Syndrome) will develop schizophrenia with the average age of onset being early-mid 20’s. Those with 22q11 Syndrome have a 25 fold increased risk to develop schizophrenia and onset is much sooner.

The statistics are similar for other associated disorders:

1 in 100 of the general population suffer with Autism Spectrum Disorders (ASD), up to 50% of 22q11 Syndrome are at risk.

3-5% of the general population suffer with Attention Deficit Hyperactivity Disorder (ADHD), in 22q11 Syndrome the risk of ADHD is 30-50%, with the inattentive type, or those with Attention Deficit Disorder, being most prevalent.

Anxiety affects 4-5% of the general population, in 22q11 Syndrome the risk again is 30-50%.

Also 25-60% of people with 22q11 Syndrome suffer from Specific Phobias, which affects less than 10% of the general population.

Children’s mental health services are fragmented and not highly funded and struggle to get recognition for the problems faced. 22q11 Syndrome is the “Cinderella” of mental health services. GP services are similar, as they believe 22q11 Syndrome presents physical issues not mental.

As children get older, if continuing with these issues without real treatment, the problems become more acute, affecting family, education, confidence levels, employment etc.

The cognitive deficiencies relating to 22q11 Syndrome are often displayed in daily living skills, dealing with money, telling the time and all feed into anxiety issues which re-enforces the findings in December’s responses of those employed, studying etc and the challenges they face.

The 2nd concerning issues is when moving into adult mental health, there is a desert of services. The Maudsley Hospital is the only place in the UK that offers adult mental health service.

Due to the extreme lack of awareness of 22q11 Syndrome, there is an extreme lack of services.

Also, the figures we are working on are based on families that are able to access a clinic in order to get help so a huge amount of cases are still unreported or undiagnosed.

Preliminary evidence in small studies by Dr Anne Bassett, University of Toronto have also suggested that 22q11 Syndrome patients are more at risk of early onset of age related conditions, Parkinson’s for example at 30 – 40 years, this would need to be picked up outside mental health services so these challenges persist throughout the entire lifespan.

Dr Alex Habel notes that a wider position has to be considered, a simple blood test will not be enough as the issues come from so many different directions.

Gillian Cassidy, 22q11 Northern Ireland, parent group, requested creating a tick list at initial stages for parents, what is available? Who do I go to first? Who can help? Contact reference points, as most parents are completely unsure as to where to start.

Claire Hennessey, Max Appeal, agreed and presented her questionnaire with 22 responses from families across the UK, highlighting current challenges;

1. Families are being referred but there are lengthy waits, nearly half of the results have waited more than 12 months to see a specialist. Then if there are mental health issues, the majority of families do not receive a formal diagnosis and the clinicians may not have heard of 22q11 Syndrome and are not familiar with the suggested management of the condition.
2. Once they are referred, 62-66% are not formally diagnosed
3. 45% have received no support or assistance managing on a long term basis
4. When asked how successful was the support in managing the behaviours relating to 22q11 Syndrome, 72% reported poor results which impacted widely on their families.

Dr Habel agrees that many fall through the cracks because the funding is a problem across all the services then the priority is just being seen, the issue is once you are seen, there are no resources in place to meet the needs required.

He agrees that early intervention and awareness is key and agrees that the cost of illness study will be invaluable. Steve Morris will present this in the next meeting.

Emma Dellow-Perry asks – has there been any discussion of linking up with other mental health groups? Especially as 22q is linked to so many of the other conditions? It was agreed this would be a great idea but presents many practical obstacles, in particular raising awareness.

Lady Herman would like to know how they are working in Scotland and will ask Phillipa Whitford MP to attend March’s meeting. Gillian did confirm that it is equally problematic throughout the UK.

It was discussed that this is something that needs to be taught at an early stage, through university curriculum and medical training.

Lady Herman suggested that we invite all the sitting MPs for all the teaching hospitals to the next meeting in order to raise awareness for this at teaching stage

1. The agreed actions were:

Speakers to be booked are to include Health Economist Steve Morris UCL

Parents “Go To” checklist to be considered

Invitation to Dr Phillipa Whitford and all sitting MPs for the teaching hospitals

5. Date of next meeting 8th March

1. AOB – - None

Lady Herman MP declared the meeting closed.