

MINUTES

All Party Parliamentary Group (APPG) on rare, genetic and undiagnosed conditions.

The impact of Covid-19 on people affected by rare, genetic and undiagnosed conditions.

When: 09:30 – 10:30, 4 November 2020, virtually

Parliamentarians

Liz Twist MP (Chair)
Catherine West MP (Vice-Chair)
Dame Cheryl Gillan MP (Vice-Chair)
Baroness Neville-Jones (Vice-Chair)
Sir George Howarth MP
Baroness Walmsley
Attendee from the office of Chris Green MP
Attendee from the office of Anne Marie Morris MP

Guest Speakers

Jayne Spink (Genetic Alliance UK)
Allison Watson, (Ring20 Research)
Tony Thornburn (Behçet's UK)
Emma Goodson (Angelman UK)

1. Welcome from Liz Twist MP

2. Annual General Meeting (AGM) of the APPG on Rare, Genetic and Undiagnosed Conditions

Parliamentarians were elected as follows:

Liz Twist MP (Chair)
Catherine West MP (Vice-Chair)
Lord Patel (Vice-Chair)

Lord Turnberg (Vice-Chair)
Dame Cheryl Gillan MP (Vice-Chair)
Alex Sobel MP (Officer)

3. Jayne Spink, Chief Executive, Genetic Alliance UK presents findings from the report 'The Rare Reality of Covid-19'

The Rare Reality of Covid-19 is a report that was published by Genetic Alliance UK in July 2020. The report found: interruptions to healthcare led to detrimental impacts on health and wellbeing; disruption to accessing routine medicines led to some having to switch medications; feelings of confusion, isolation and abandonment amongst those with rare conditions due to poor communication surrounding shielding guidance. Remote healthcare is widely welcomed by the community but there must be an acknowledgement that it cannot entirely replace face-to-face consultations and must not be used as a cost saving activity in the future. The community have also expressed issues relating to accessing support and education for children with complex needs during Covid-19. There are still issues with getting children that require Aerosol Generating Procedures (AGPs) back into school. Issued guidance is not realistic or practical in many school settings and leads to those children being excluded from attending school.

Genetic Alliance UK calls for: a collection of morbidity and mortality data to enable a better assessment of the impact of Covid-19 on people living with rare conditions, priority access for those with rare conditions to Covid-19 tests if they have a legitimate reason to ask for a test, guaranteed access to PPE for those living with a rare condition and those that care or support them. There is also a call, for when a Covid-19 vaccine becomes available, for those with rare conditions to be considered for priority access.

There also needs to be more support for those who choose to self-isolate due to their condition. There are learnings from this crisis that should be included in the Rare Disease Framework that is due to be published by the end of the year.

Jayne's presentation was followed by a short discussion surrounding the possibility of collecting data regarding specific disease types and if they have been more impacted than others by Covid-19. Suggestions were also made to contact the Health and Social Care Select Committee on the lack of response to Genetic Alliance UK's letter to the Secretary of State. Other suggestions included, sending 'The Rare Reality of Covid-19' report to other MPs and onto the Public Accounts Committee as part of their investigation into the Government's handling of the Covid-19 crisis.

4. Allison Watson, CO-Founder and Trustee of Ring20 Research and Support presents on how the charity has supported their community during Covid-19

Ring20 is a very rare form of epilepsy that is difficult to treat and diagnose. There is no set prevalence and is likely to be under-reported across the world. The key aims of Ring20 Research and Support are to signpost individuals to accurate information, contribute to research in the field and connect families so they can support each other.

Due to the lack of information that is available on this condition, many people affected by Ring20 were confused as to their vulnerability to Covid-19; this led to fear and confusion over if they should shield or not. Important research projects that have had years of crowdfunding have been put on hold. The organisation found that it had a large increase in demand for their

services with a decrease in funding and a decrease in resources as many volunteers left to prioritise their families.

Allison called for the new Rare Disease Framework to include ultra-rare conditions and outline how those affected with these conditions will be supported.

5. Tony Thornburn, Behçet's UK presents on shielding with a rare condition.

Behçet's is a condition that varies in symptoms, treatments and responses to treatments. Those affected will often have relapses of the condition that can flare up due to multiple different factors one of which is stress.

The timing and guidance surrounding the announcements of shielding were not thought through and led to confusion amongst the community. There was a sense that these measures were reactive rather than proactive. There appears to be a lack of science and evidence behind the guidance. The inconsistency across the four nations surrounding shielding has led to frustration and further confusion.

6. Emma Goodson, Trustee of Angelman UK speaks about accessing educational support.

Angelman is a rare neurological condition that results in severe intellectual and physical disabilities. There is not a direct link between Angelman and vulnerability to Covid-19 but in many cases, children with Angelman have other complex medical needs that do make Covid-19 more of a risk. For example, Emma's son has epilepsy and a lung condition in addition to Angelman syndrome.

During the crisis, Emma lost access to all support services. Emma's son requires AGPs and there have been problems surrounding what constitutes as an AGP. One example is oral suctioning which includes the removal of excess saliva when the child or young person is not able to swallow, sometimes this can occur during an epileptic episode.

There is guidance on AGPs but it is not consistently applied across the county. Some schools are able to accommodate the necessary requirements, such as having a separate designated room for these procedures, higher quality PPE and suitably trained staff, which works if it's a planned procedure, but not in emergency scenarios. In addition, many schools do not have the facilities to accommodate these requirements and so children are asked not to attend school. To add to the confusion and frustration, educational support is a 'postcode lottery'. In some areas Zoom interactions with teachers is allowed but in Emma's local area, due to a safeguarding policy, virtual contact with these children is not allowed and therefore Emma's son has not received educational support for the last seven months. Emma mentions that there is an assumption her child has Covid-19 just because he requires medical attention. Other children at the school that do not require AGPs will still cough, sneeze, spit within a shared classroom. Children with these complex medical needs have a right to an education.

7. Liz Twist MP updates the group on recent APPG activities.

Liz Twist MP has tabled written parliamentary questions regarding; priority access for those with rare conditions when a Covid-19 vaccine becomes available, guidance for schools on AGPs, and how many pupils are unable to attend school as a result of needing AGPs.

Liz Twist MP shares that she hopes to get a debate on the impact of Covid-19 on those affected by rare conditions.

8. Discussion

Points were raised regarding delays in personal payments and people having to take statutory sick pay because they are vulnerable due to their condition and cannot work from home. People are having to choose between livelihood and health.

Other issues were raised surrounding those who are vulnerable while at university. One example was given from someone with a rare chronic lung condition. The individual had started university but there was an outbreak of Covid-19 on the campus and when she asked for support to shield, she was told that the university can only provide support for self-isolation for two weeks not prolonged shielding.

There was acknowledgement across the group that accessing sufficient funding for suitably qualified carers has been particularly difficult. Even if you follow the protocols and processes to receive help, there physically are not enough carers to go round that are qualified for complex needs. This issue is not just Covid-19 related but also a longer-term issue.

Liz Twist MP suggests that people with specific concerns and issues can contact their MP and we can increase awareness that way. This will also help with the likelihood of getting a debate in the House of Commons surrounding the impact Covid-19 has had on those affected by rare, genetic and undiagnosed conditions.