

COMMUNITY CHECK-IN NOTES

Tuesday 10 November: England's second phase of lockdown

Organisations represented

- Duchenne Family Support Group
- Hereditary Spastic Paraplegia Group
- Pitt Hopkins UK
- PKD Charity
- Smith-Magenis Syndrome Foundation UK
- SWAN UK
- Unique
- Wolfram Syndrome UK

Genetic Alliance UK staff attending:

- Nick Meade, Directory of Policy
- Lauren Roberts, Director of Support and Engagement
- Farhana Ali, Public Affairs Manager
- Natalie Frankish, Policy and Engagement Manager – Scotland
- Louise Coleman, Policy Analyst
- Jan Bochinski, Fundraising Manager
- Emma Hughes, Policy and Engagement Manager – Wales
- Sophie Peet, Policy and Public Affairs Officer
- Jennifer Jones, Researcher
- Izzy Rundle, Support and Engagement Officer

NM welcomes attendees and introduces the session on the second England-wide lockdown and discussion on how this is affecting our community.

Aerosol generating procedures (NM)

- Genetic Alliance UK worked with Liz Twist MP to submit a number of written parliamentary questions to the Department of Education on aerosol generating procedures (AGPs). These questions received a detailed response from Vicky Ford MP and we are pleased this is on the Government's agenda.

Genetic Alliance UK

contactus@geneticalliance.org.uk
www.geneticalliance.org.uk

Registered charity numbers: 1114195 and SC039299
Registered company number: 05772999

- WellChild have drafted a letter to go to MPs. **ACTION: Genetic Alliance UK to follow up with WellChild** as we still believe there is value in undertaking a letter writing campaign to MPs on AGPs.
- Attendees received an update from the recent All Party Parliamentary Group on Rare, Genetic and Undiagnosed Conditions meeting which also discussed APGs.
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Country Specific Updates

Louise Coleman, guidance in England

- A number of conditions have been added to the extremely vulnerable category and others have been taken away (mainly those related to children).
- Guidance is now focussed on the *individual* rather than *households*. For example an individual can be shielding in a household whilst another individual attends school.

Emma Hughes, guidance in Wales

- Two-week-long 'firebreak lockdown' has just ended in Wales.
- There was no reintroduction of shielding.
- A new email/text service has been launched in Wales and people have been asked to sign up to that service, so that the most up to date information can be shared rapidly.

Natalie Frankish, guidance in Scotland

- Tier system of restrictions currently in place in Scotland.
- More information to be released imminently regarding the Tiers e.g. and if areas will move to higher levels of restriction.
- The Scottish Government is not requesting any groups to shield. Additional support is available to more vulnerable groups via Local Authorities.

Community Experiences

Isabel Rundle – SWAN UK

- Many SWAN UK families whose children are in the clinically extremely vulnerable category are being told to send their children to school, despite having to shield previously.
- Some of these children have caught Covid-19.
- Previously shielding families now have siblings going to school and parents going to work and bringing Covid-19 home.
- Parents are concerned about how coronavirus will affect their children and long-term effects this will have, especially as they have conditions for which there is little information.
- Parents are receiving unclear and mixed messaging about whether to send their children to school.

Discussion:

- (Participant) two siblings with Duchenne Muscular Dystrophy have received separate letters with differing shielding advice. Parent is bewildered and doesn't know what to do.

- (Participant) guidance from the Royal College of Paediatrics and Child Health does not mention children with developmental delay, intellectual disability and those who cannot shield. The RCPCH has taken this on board and will look to share adapted guidance. Unique has also requested an easy to read format too.
- (LR) how do parents who need to self-isolate look after children with additional needs? What makes the house safe again?
- **ACTION: Genetic Alliance UK will find this information and share this on the Hub.**

What can Genetic Alliance UK do to help?

- (Participant) How do children self-isolate, what about those with challenging behaviour? What guidance is there? What do you do when your child has been close to someone who has tested positive for Covid-19 but hasn't been told to self-isolate? Simplified guidance on this issue would be particularly helpful.
- (Participant) We've gone backwards on some issues, people are wondering if they can have carers working in their home. Some schools are saying that they cannot provide physio because of Covid-19.
- (Participant) Private physio seems to continue but not NHS. Not providing physiotherapy is akin to denying patients access to medicines.
- (Participant) Some families are not receiving Covid-19 test results, some are waiting ten days or more, by which time the results are useless.

COVID-19 Vaccines

- NM notes that a vaccine that is 90 percent effective has been developed.
- Trials are continuing so this number might change.
- Questions remain regarding efficacy in different population groups.
- Vaccine comes in two parts e.g. two doses.
- The Joint Committee on Vaccination and Immunisation (JCVI) interim advice prioritises in age order (eldest first), which the JCVI recognises is flawed.
- Genetic Alliance UK requested that Liz Twist MP ask a question on this issue.
- Whilst the answer to the question is predictable we are pleased that rare, genetic and undiagnosed conditions have been brought to the attention of the JCVI.
- We have spoken to the Neurological Alliance and will seek further clarification regarding carers' access to the vaccine.
- **Action: Genetic Alliance UK to follow up parliamentary questions focussing on disabled children and their carers and personal assistants (as a priority group to access the vaccine). A joint letter to JCVI following first parliamentary questions offering support and information. A joint statement (a public document) to stress the need for a vaccine and the need for the rare disease community.**

Discussion

- (Participant) Baroness Thomas is active on the Muscular Dystrophy APPG and may be willing to ask parliamentary questions.
- **Action: Genetic Alliance UK to contact Baroness Thomas of Winchester.**
- (Participant) People are worried about the vaccine and the impact this will have.

- (Participant) What process is the vaccine going to go through, the safety and regulations, how can it be fast tracked and the due diligence that is being taken?
- **Action: Genetic Alliance UK to produce this information.**

Zoom transcript:

- Link to PQ here: <https://questions-statements.parliament.uk/written-questions/detail/2020-10-30/109564>
- Liz Twist is part of the neuromuscular APPG so will be a good MP as very supportive
- Updated links / summary for England: <https://covid-19.geneticalliance.org.uk/england/>
- Updated link / summary for Wales: <https://covid-19.geneticalliance.org.uk/wales/>
- Updated links / summary for Scotland: <https://covid-19.geneticalliance.org.uk/scotland/>
- Latest letter sent out from Welsh Chief Medical Officer to those on shielding list: <https://gov.wales/sites/default/files/inline-documents/2020-10/letter.pdf>
- I've since had a chance to read up on the trials, and they are healthy adults only.
- Didn't Boris Johnson say health workers would be first? [for vaccine]
- Baroness Thomas works with us and Liz Twist and may be able to ask a question in the house
- Surely carers are on the frontline too!
- Care workers are number one, health workers number two on vaccine list.
- Parents need to be included
- Free webinar by Royal Society of Medicine on vaccine on Thursday: <https://bit.ly/2lcYxXr>