

COMMUNITY CHECK-IN NOTES

Tuesday 16 June: Impact of Covid-19

Organisations represented:

- Action Duchenne
- Alex TLC
- Alström Syndrome UK
- Angelman UK
- Archangel MLD trust
- Behçet's UK
- Cerebra/Cardiff University
- CMT UK (Charcot-Marie Tooth)
- Duchenne Family Support Group
- Polycystic Kidney Disease (PKD) UK
- Pitt Hopkins UK
- Ring20 Research and Support UK
- SOFT UK
- UK Mastocytosis Support Group
- Unique – the rare chromosome and gene disorder support group
- Wolfram Syndrome UK

Genetic Alliance UK staff attending:

- Jayne Spink (JS), Chief Executive (JS)
- Nick Meade, Director of Policy (NM)
- Lauren Roberts, Director of Support (LR)
- Amy Hunter, Director of Research (AH)
- Natalie Frankish, Policy and Engagement Manager – Scotland (NF)
- Emma Hughes, Policy and Engagement Manager – Wales (EH)

Introduction

JS welcomes everyone and introduces Small Charities Week. Notes we will be looking at the impact of Covid-19 on small charities and providing a sneak preview of results of the EURORDIS Rare Barometer Covid-19 survey. AH will also give update on Genetic Alliance UK's CEO survey and the initial findings. JS notes that, as usual, will be posting weekly updates for England, Scotland and Wales on the hub: covid-19.geneticalliance.org.uk/news.

EURORDIS Rare Barometer Survey Results

JS notes that we promoted this survey earlier in the year, data was sealed on 24 May 2020. There were 141 UK respondents, the key results are:

Genetic Alliance UK

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

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

- Level of threat of Covid-19.
- Survey finds high level of disruption in aspects of care provided by health professionals (esp. rehabilitation therapies, appointments with GPs).
- Many people report detriment to their wellbeing as a result of healthcare interruptions (around 5% say potentially life threatening).
- Access to medicines - 1 in 5 have experienced a disruption to access to taken medicines.
- Impact on hospital care - half fearful of attending hospital in case catch Covid-19, many hospitals and units closed - around 17% note that the necessary materials needed for their care had been missing as it was used for Covid-19 patients.

Genetic Alliance UK will be producing an impact report based on these findings in the next few weeks.

Comments:

- Surprise that a low number of transplants were cancelled - notes only 4 hospitals in UK were open for organ transplants. JS noted that this may not be a representative statistic, need to know context of question and respondents.

Genetic Alliance UK CEO Survey

- Genetic Alliance UK wanted to find out how Covid-19 impacted our members.
- Acknowledgement to Cancer52 - we adapted their similar survey.
- 10 respondents at this stage to give flavour of responses/questions - targeted at leaders of organisations. If people still want to complete the survey is open until 5pm on Monday 22 June: surveymonkey.co.uk/r/geneticallianceuk_impactofcovid19_
- 4/10 charities feel demand has increased between 25 and 50% - demand for information is biggest increase
- 7/10 have seen, or predict, a fall in income. 0/10 have not accessed funding support from Government. 3/10 worry about long term future of organisation.
- Patients most concerned about - confusion on shielding, concern about catching virus, accessing treatment if they do become ill, financial impact, reopening schools, support for children with SEN/ASN. Others raised concern about impact on care, mental health and the long term reinstatement of services.
- Positive new ways of working - 8/10 identified new ways of working (Zoom etc), scope for remote clinics when needed, social impact of increased video calls with family, friends etc.

Comments

- JS raises concerns about impact across the wider community of Genetic Alliance UK members.
- Question on demand on services is hard to answer (because genetic centres closed, new referrals fell) - but the type of questions were of greater intensity (longer calls, repeated emails, more support required). Asked about government funding and support (JS explained that there have been some funds in Scotland distributed by Scottish Government and a number distributed throughout England by various local bodies). Some organisations fell between two stools, so could only benefit from furlough.
- JS notes the benefit of funding to help with Covid-19 response - but highlights long term impact on project funding and finding financial support to undertake 'usual' work and projects. Notes comments in chat about the limitations of local community funding for national charities, a disadvantage for rare disease charities.
- AH invites members to share experiences and complete survey to further inform the report.

Open Discussion

- JS provides update from BBC - no longer going to cover a story on children going back to school due to the recent policy change (but may return to at end of summer). JS notes will share our impact report in hope of another story being picked up.
- Concerns from some communities about going back to work/school due to impact of cleaning chemicals - looking for legal standpoint/guidance on what should be provided. What are the guidelines/rules for businesses and schools?
- Talk about the changing guidance on shielding. People were expecting government to make an announcement this week - but only RCPCH seems to have been updated. Notes different guidance and extensions in Scotland and Wales.
- Notes on several Facebook pages, lots of concerns. Concerns there is no science behind downgrading of guidance. Still no scope for support for those shielding (i.e social bubbles). How do we know who is shielding and in what category? JS asks - do you feel you can trust in the decision to change guidelines and downgrade – response that there is more trust in RCPCH guidance than Government guidance. Notes that families supported don't trust the government because they feel that guidance is changing too quickly without justification. Worries that people are moving to more of a distrust/conspiracy/misinformation viewpoint.
- There are contradictions and disparities across UK including scientific/medical bodies offering contradicting advice. Advice from consultants also is not always consistent.
- JS notes all the nuances required for personal risk assessment/decision making.
- Most families are saying 'no one has told me not to shield, so I'm staying home as too scared to risk it'. No one wants to risk the sacrifice of the last 12 weeks, but notes that the impact on families is very significant. There is a craving for robust guidance and clarity on respite services resuming.
- Comment that the British society of Rheumatology conference that clinicians were very cautious at the beginning of guidance but less worried now - notes the importance of clear information on condition-specific risk and knowledge of local Covid-19 infection rates.
- NM has written to RCPCH and BSGM for clarity - acknowledges likely that guidance from other bodies will follow and that due to rapidly changing situation this may result in apparently contradictory advice.

Comments from Zoom chat

- NLCF are now managing some government funding.
- We were told yesterday that because most of our beneficiaries are not located in our county, we are not eligible to apply for our local UK Communities Fund. This would apply to many GAUK groups I suspect. We have a Lottery application in, awaiting response.
- We are also unable to apply to local community funding through the National Emergencies Trust (NET) as we are national charity. Not suitable for rare diseases.
- Quote from one of our Mums is reflective of the situation: 'I can't trust anything the government says because it's always changing and contradicting. I won't do anything that will risk the girls until we know it is truly safe to do so. We are missing respite as it hasn't been safe to have the carer come in and we haven't had any other support.'
- Disparity between clinicians- so don't think they are really sure, some are saying extend to August, others are saying individual risk on what meds your children are on...
- I mentioned at Natalie's very useful Scottish Zoom meeting yesterday; A fundamental factor is the 'flash-to-bang time' from contracting to symptoms emerging, and therefore potentially re-infecting others (which could be up to 2 weeks) which causes difficulty. This is for both

Vulnerable and Extremely Vulnerable category. If two fielding groups met up, for example, there is no additional risk – providing both are certain that the other part could not have done anything to become infected (in the last two weeks). So until time reveals what happens after restrictions are relaxed, it will be difficult for individuals to judge – about risks or not to accept. Also if one had an accurate ‘map’ of what is going on in their area (incidence et al) rather than ‘county, or city wide’, generalised statistics, one could judge better.

- Definitely need more transparency, less subterfuge and consistent message across all medical bodies.