

COMMUNITY CHECK-IN NOTES

Tuesday 15 September: Hosting online events

Organisations represented:

- Behcet's UK
- Duchenne Family Support Group
- Hypermobility Syndromes Association
- Pitt Hopkins UK
- PKD Charity
- Ring20 Research and Support UK
- Same but Different
- The Smith-Magenis Syndrome Foundation UK
- The UK Mastocytosis Support Group
- Wolfram Syndrome UK

Genetic Alliance UK staff attending:

- Jayne Spink (JS), Chief Executive
- Amy Hunter, Director of Policy
- Lauren Roberts, Director of Policy
- Nick Meade, Director of Policy
- Farhana Ali, Public Affairs Manager
- Natalie Frankish, Policy and Engagement Manager – Scotland
- Emma Hughes, Policy and Engagement Manager – Wales
- Jennifer Jones, Researcher
- Sophie Peet, Policy and Public Affairs Officer
- Izzy Rundle, Communications and Support Officer

Jayne Spink (JS) welcomes all to a meeting to discuss hosting online engagement events.

Presentation from Susan Muir (SM) from PKD Charity

- SM provides an overview of the support service offered by PKD (pre-Covid), including a peer support program that centered on meet-ups for members.
- Their support program was thrown into a spin in March as the Covid-19 situation developed and led to a need to move from face-to-face meetings to Zoom.
- Zoom meet ups are hosted by a 'group host', regionally.
- To address the gap in some areas, PKD offered 'community elevenses' for people across the UK to join.

Genetic Alliance UK

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

- SM notes that there is a difference in hosting through zoom, but in general these differences have been positive.
- SM notes that they offer a mix of webinars and time to chat sessions. In some cases, these have been merged where presenters come along, give a short presentation, then there is time to chat afterwards.
- SM aims to deliver 4-6 information and support sessions throughout the year.
- SM notes there won't be any face-to-face meetings between now and March. Zoom meetings will allow for safely-distanced engagement but are also an offset of costs – with a reduced income, delivering events by Zoom is helpful.
- The benefit of Zoom meetings is that we can bring professionals to patients for all the UK, not just for the local area.

Presentation from Caroline Heap (CH) from SOFT UK

- CH tells us that SOFT UK have included new zoom catch ups in the support they provide. CH thanks LR and JS for their support with this.
- Zoom catch ups were developed in response to engagement with families through SOFT UK's Social Media Officer. Some sessions were very general, others were topic specific.
- Social Media Officer sent mugs to each family with a tea bag, biscuit and little handwritten note to those joining – each call starts with a 'cheers'.
- CH notes the importance of setting guidelines and expectations - i.e muting, what happens if connection goes, using the chat.
- CH stresses the importance of having a host that can encourage engagement and manage very chatty people.
- CH notes that people were very up for talking and sharing experiencing
- JS notes the variety of ways online engagement can be delivered.
- SM notes that peer support and befriending sessions have been helpful.

Discussion:

- Participant asks about safeguarding.
- SM notes that safeguarding policies are in place, but DBS checks aren't required because sessions are not one-to-one.
- SM notes that on some calls they 'plant' someone that they know will generate and contribute to discussion to help things move along if there are any quiet times, although SM notes that most calls are very lively.
- Groups shared their various experiences/concerns about safeguarding policies. LR says Genetic Alliance UK are updating their safeguarding policy and will share and encourage group members to share their examples on the Facebook page to help build resources.
- SM notes that you can have people pre-register to attend a meeting by Zoom but only on a professional account. SM says that this is helpful for safeguarding.
- Participant asks about timing for a meeting – should it be week or weekend? SM says typically they would go for weekends and that Sunday afternoons have most attendance. SM notes families with young children probably don't want to do early evening. CH notes that they polled their families and weekdays aren't popular, but evenings are difficult too.
- Participant says they have been doing fortnightly catch ups with families which has been a positive experience. They are keen to expand this to offer a service to young adults (over 18/early 20s) and want to try a pilot session.

AOB

- JS invites experiences from members on how they work with youth groups. Participant notes Muscular Dystrophy UK's 'Trail Blazers' Group and DMD pathfinders. Notes that she can put JS in touch with as they would be an asset to our discussions.
- LR notes Genetic Alliance UK are looking to increase youth engagement. LR suggests a community catch up meeting on this topic.
- JS invites members to join an email group by putting their details in the chat.
- JS thanks everyone for contributing and explains we will now put together top tips for sharing.
- JS reminds that next week is a session on returning to the clinic and the following week will be focused on genomic services across the UK. We will add youth ambassadors and youth support.
- NO asks if anyone is planning a physical meeting anytime soon - SMS are planning on a physical meeting next May. General consensus is no. SM notes impact on safeguarding if bringing people together.

Discussion from Zoom chat

- Children in Need have a virtual safeguarding check list
- Yes, we saw that (CiN), when applying and that triggered our thorough investigation. Whilst high level principles are fine, it's when one gets into the detail that potential issues arise. We have previously tended to get round the problem with children by stipulating that a parent must be present. Just waiting for the first child to ring our helpline!
- A couple of the Duchenne charities have done gaming days where they do an online tournament...and make new friends
- Zoom chats - tried different times - Coffee mornings, free for tea at three, wine with wine at nine, mens den at ten. Have stuck with 9pm on Weds and Sundays. Use the 3pm slot for guests weekdays and quizzes/events at weekends on less frequent basis.