

COMMUNITY CHECK-IN NOTES

Tuesday 27 October: Rare Disease Day 2021

Organisations represented

- Alstrom Syndrome UK
- AOFAC Foundation
- Aortic Dissection Awareness UK & Ireland
- Behcet's UK
- CMT UK
- Cystic Fibrosis Trust
- Dravet Syndrome UK
- Duchenne Family Support Group
- Ehlers-Danlos Society
- Findacure
- Hereditary Spastic Paraplegia Group
- Idiopathic Intracranial Hypertension UK
- M4RD
-
- OcuMel UK
- PCD Family Support Group
- Pitt Hopkins UK
- PKD Charity
- Ring20
- Same but Different
- SWAN UK
- The Leukodystrophy Charity
- The UK Mastocytosis Support Group
- The Pituitary Foundation Twitter
- Timothy Syndrome Alliance
- Unique
- Wolfram Syndrome UK

Genetic Alliance UK staff attending:

- Jayne Spink (JS), Chief Executive
- Nick Meade, Directory of Policy
- 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, Communications and Support Officer

NM welcomes attendees

- This meeting is to discuss plans for Rare Disease Day (RDD) 2021 and we wanted to involve stakeholders in the planning process.

Genetic Alliance UK

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

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

- Great to see so many here, please make use of the chat as there might not be time to hear everyone speak.
- We will be recording for note taking purposes only.

LR introduces the session

- FA will outline what EURORDIS are planning for Rare Disease Day 2021.
- I wanted to talk about how we can translate that to the UK setting.
- We've never involved stakeholders this early in the process before and we wanted to do it this year for two reasons. Firstly, while we have these community check-ins, thought it would be a good utilisation of this space to gather feedback and ideas.
- Secondly, wanted to gather opinions on the change of focus for next year's Rare Disease Day.

FA presentation on EURORDIS Rare Disease Day 2021

- EURORDIS are the European organisation for rare diseases and coordinate Rare Disease Day globally.
- Unfortunately we can't share the visuals for their campaign with you just yet as they're still being worked on.
- Wanted to highlight that they will be more customisable than in previous years so you will be able to tailor them for your specific condition if that is appropriate for your organisation.
- You will be able to download posters and recreate them in your own branding but you don't have to, can simply use the posters directly.
- Previously, we've done our own Rare Disease Day campaigns but this year we want to be more closely aligned with EURORDIS campaign as we think the visuals and messaging are applicable to the UK.
- We also see an opportunity to show solidarity with Europe in the context of Brexit.
- Note - you can use the EURORDIS logo for fundraising but not for commercial purposes.
- For Rare Disease Day 2021 we want to have the messaging of coming together and being stronger together as a community and want to reach out to the wider public.
- Previous years we haven't aligned with the EURORDIS campaign as visuals have not been representative of the UK but this year the visuals are diverse and the campaign will have ten case studies, one of which we hope will be from the UK.
- This campaign will also focus on the range of emotions associated with these case studies, not just the celebratory side of things like in previous years.

Key messages of the EURORDIS campaign:

- Rare is many
- Rare is strong
- Rare is proud
- Alongside the slogan 'show your colours' and #RareDiseaseDay

Timetable:

- Official launch is 100 days before RDD
- Wed 18 November – access to case studies and illustrations

- EURORDIS will disseminate the visuals and assets as they are ready so will be drip fed leading up to Rare Disease Day
- Materials will be available to download from their website
- They have hosted a webinar that is available to watch on preparing your digital comms for Rare Disease Day. There will be another on 19 November on lighting up public buildings and there will be third on engaging with media that doesn't have a set date yet.

LR presents Rare Disease UK ideas for 2021

- Overview of Genetic Alliance UK and Rare Disease UK.
- Genetic Alliance UK is the charity that runs the Rare Disease UK campaign.
- Focus for Rare Disease Day 2021 is storytelling as we think that's the best way to convey what it's like to have a rare condition and is the most engaging with the public.
- Want to look at how to apply the EURORDIS campaign to the UK setting
- Previous years focus on the celebration of the rare community and the achievements and has a very positive message. This year want to approach it differently, want it to be more hard hitting but not lose that celebratory feel.
- Want to express the challenges particularly in the light of Covid-19 – focus on the difficulties, shielding etc. May be able to use Covid-19 as a 'springboard' as the general public all have concerns for health at the moment and we might be able to draw a connection and gain empathy from the general public.
- Last year, we found it difficult to gain traction in the press. In the past we've found that the press is more interested in the negative stories and the harder hitting stories. Want to gather opinions about how you feel about this, how to approach it sensitively and what line should we not cross.

Rare is many:

- Want to demonstrate a united front especially in light of Brexit.
- Want to create a close network and connect on social media.
- Last year we had the Rare Film Festival which was great at uniting and raising awareness. Got lots of materials that we can promote on social media. Decided not to run it annually as filmmaking is very time consuming so won't be one this year.
- Instead thinking of having an online storytelling competition with different categories such as visual, written etc. maybe a sibling/young person category.
- Hoping to launch in Jan for entries, panel to judge and a public vote. Results released on Rare Disease Day 2021 and this also will generate lots of content in the run up to the day.

Rare is Proud:

- Want help to communicate the pride in size and diversity of the rare disease community. How we can work together to show pride.
- Promote each other's work, engage on social media or generate Instagram pods to work with the algorithms?
- We would like to have a discussion today and come back in a few weeks with some more solid plans.

NM opens the floor for discussion

- Agrees that the public will be more involved with hard hitting stories, if they can feel something whether it's positive or negative.

- Need to be careful we don't fall into the category of completely shocking the audience - they run 'Surviving and Thriving' section in a newsletter where they share stories. There is a way to thrive with the right support. Covid-19 can be a useful springboard but be cautious not to disappear/be drowned out by Covid-19, otherwise the impact will fade fairly quickly amongst the general public.
- Agree with the above. Covid-19 is a good platform, similarities between Covid-19 journey and rare disease journey. Back in March/April you may have had a condition that you know nothing about etc. and have had life restricted. Many people with rare conditions have those restrictions - 'welcome to our world' feeling.
- Agrees with specific stories ideas, very relatable at the moment with regards to shielding etc. Asks what about a call for action for income/fundraising - impact of Covid-19 on charities and demonstrate how charities have stepped up and supported communities - show 'value for money'.
- Gareth Owens - Supports the story telling idea - powerful. There are two types of stories, negative/tragic or positive/triumph through adversity - media often focus more on the negative. Also, we can't ignore Covid-19 so it makes sense to use it but given it is not a rare disease itself maybe we can focus more on the impact Covid-19 has had on the community. For example, normal healthcare has been disrupted and the impacts of that.
- LR agrees that there are two types of patient stories and press interested in the negative. How about we approach it like this: do the negative/tragic stories for the press but with social media and our comms can be the positive triumphs?
- SLP Yes media focus on the negative because it generates more selling power on screen and print but also does enjoy life affirming stories. Broad context - last year was difficult to get traction. They want real stories not the generics. Health journalists don't have interest in generics at the moment. Could incorporate individual stories within generics - differ depending on geographical location perhaps?
- If you really want hard hitting stories you can draw comparisons between fear of dying of Covid-19 and fear of dying from certain rare conditions. There are also some positives to draw out like compassionate use of medicines and repurposing medicines - people with rare conditions have been utilising these services for a while but now the general public have more awareness of this as it's being used for Covid-19.
- Rare disease patient journey is very similar to the COVID patient journey.
 - 1- early diagnosis is key
 - 2 - Access to innovative medicines
 - 3 - Expert medical centres
 - 4 - Centres where research is a priority.

Covid-19 has been a sort of 'blessing' in the sense that the virtual nature of everything has enabled me to attend more events than I would normally be able to due to my condition. The general public now has a greater understanding of the immune system and antibodies - that relates to my condition - and more and more research is being done in these areas. Drug repurposing is being looked at more in light of Covid-19.
- Need to be careful and protect those individuals that come forward for press/media case studies. In the past we've had press camping at individuals' doorsteps, receiving global attention but in a very disruptive way.
- There could be an opportunity to be quite critical of the government given we're not doing the face to face parliamentary events. What are the outcomes for the day? What would be classed as a success?

- Open the dialogue, making people have those difficult conversations, open the door for people to learn more and then they are better able to support. Opportunity to make rare diseases more 'human' and not just something you see in scientific journals.
- We can take advantage of the fact that the public are more aware of 'invisible conditions', people don't always 'look' sick, similar to Covid-19 asymptomatic carriers, don't look sick
- Has there been any traction with celebrities? Can be good for increasing awareness.
- We take on the view from healthcare professionals and children - raised issues around tracheostomies in schools at the moment. They have an appeal for more transitional nurses - some celebrity support on this topic.
- What are the calls to action for Rare Disease Day? Awareness?
- NM there are some public affairs work going on in the background with the rare disease framework and political messaging but Rare Disease Day is bigger than that.
- LR Mainly aiming for increase in awareness amongst the general public. Understand → Care → Do. Public needs to understand the topic, then they are able to care/empathise then they can do something to help/support/fundraise etc. Good examples of these are mental health awareness and cancer. This was helped by celebrity engagements also. We're still at the understanding phase with the general public for rare diseases.
- JS Understand that people guard celebrity contacts to help own causes but perhaps if we are able to ask for a small favour and organise a coordinated push. E.g. a very short video for Rare Disease Day 2021 and all of us promote/push it on social media.
- Sounds like we have good momentum and it will be an impactful Rare Disease Day 2021 that will have lasting effects throughout the rest of the year.
- LR We would like to do this sort of discussion relatively regularly and check in on progress etc. People who are willing to help and support in detail, leg work type of support e.g proofing wording of messages. Suggest we come back in one month and share what plans we have, hopefully more solidified by then. We'll pull out themes and align interests and experiences with people who would like to help. Use the contactus@geneticalliance.org.uk to get in touch.

Zoom transcript:

- I know a lot of the PCD community are a bit fed up of the 'keep calm and carry on', 'chin up, it's fine' vibe
- Linking it specifically to the impact of Covid may attract media attention
- I think piggy backing on the Covid-19 research focus is a fantastic opportunity for our rare disease community.
- I do think this has to be done carefully so that we don't create an environment where rare diseases disappear when Covid does.
- Yes, working together is key.
- All sounds good. Building on this discussion to share here's a video Dravet Syndrome UK produced over the summer about the impact of COVID on our community <https://www.dravet.org.uk/news/living-dravet-syndrome-during-covid-19-lockdown/>
- Is there a need for a social media training webinar or similar so each organisation can be as impactful as possible and help/interact with each other on social media
- A question. Will there be a call to action around giving to charities? Given the extent to which our income is being hit?
- Good idea, I am not the best at social media
- Like the idea of more hard hitting.

- And not too keen on letting the government off the hook for what's not being done for rare diseases by going and let them celebrate their "work."
- I think we need to know how common rare diseases are. I have heard of many that I thought were common, but then I found they were rare
- I can't seem to put my hand up. I have a thought on the Covid-19 idea
- I am happy to share my daughter story, however she hasn't been affected by Covid-19 as her treatment (gene therapy) works really well so far
- Yes - it's "Welcome to our World"!
- There is the strong potential to hook around the isolation angle too - many RD patients have lived with this for years, now everyone has some small insight into that. So agree with this.
- Our charity core work has been taken away with Covid-19, as our main role is support, and we do this by meeting up together as families in a social setting such as day at races etc. As well as subsidised holidays. So not only have we lost our income but we have had to re-jig how we work completely
- Just a thought to share is that our comms reach pre-Covid was extremely strong and an expectation is that post Covid-19 the environment (media-wise) will return to something more "normal".
- From my experience generally speaking, people hear the word 'rare' and switch off and the default is to think it won't doesn't affect me. So I think the emphasis on 'many' is important in next year's campaign and emotive storytelling will help people to relate and connect.
- : I notice that some of the bigger charities have collaborated to put pressure on the government to provide more support for those who were shielding and are now forced to go back to work – given that there is usually a rare disease day reception, it could be an opportunity for us to add to this collective pressure to this
- Denial of healthcare is definitely an important point!
- True but also true of other diseases that aren't rare such as cancer. Which is well known to the public.
- So may not get much sympathy for rare diseases through that route
- I think to cut through this year without telling the hard hitting human story unfortunately we won't get any press coverage. And ultimately it is hard hitting. People from the rare disease community are disproportionately impacted compared to the general public. It's harder to get a diagnosis, it's harder to access treatment, social isolation is even more exacerbated.
- Covid-19 has caused a lack of access to treatment. Some people have died as a result of not being able to get healthcare.
- If some rare diseases don't lead to death many RD's do remain with individuals for their life as a chronic lifelong debilitating condition, that maybe relates to long, Covid-19 and the public's fears of that
- Poorly known condition, limited research, no evidence based treatment, fear of dying, fear of your family having it, test results not backing up what you know to be true - all parallel Covid-19 and rare diseases
- We have had some media success using contrasting patient stories, e.g. person A had an Aortic Dissection, was misdiagnosed and tragically died; person B had the same condition, was promptly diagnosed and treated and lived.
- Add in Long Covid and you have persistent condition for some that shouldn't be forgotten because it's not acute.
- And then you can show how resilient people in the RD community are because they always have to deal with these limitations. The new normal. Was their normal

- I was typing: What is the key point or points that we want to get across about Rare Diseases (at this time); that lies behind the three themes you have listed? That should help shape our strategy.
- On the topic of Covid, we could approach a discussion with the mental/ psychological impact of rare disease and connect with how people are currently feeling now with Covid. (and the long term impact of that.)
- What about the people have more than one rare disease that are from different medical disciplines
- Not sure of other people's experience, but we have had a huge drop off in engagement from our community with regards to our social media posts/campaigns. Likely due to exhaustion from Covid-19 posts and use of digital devices! We saw significantly higher numbers when it came to positive/fun content and individual stories (which our respective community members always get behind!) As mentioned a two pronged approach may be best for our individual organisation's approach for community members and the tone of what we pitch to the media.
- There are two parts to this proposal - leveraging Covid-19 and its parallels to rare diseases as a hook; and cutting through the general noise on Covid-19 to secure press coverage. We have some experience already in talking about the parallels. Just talking about Covid-19 isn't enough necessarily to get media pick up. It doesn't need to be about spotlighting individual families - of course families come first. But it will be difficult to get cut through without being hard-hitting in our messaging.
- Is the APPG still live?
- The APPG is very much still alive.
- Yes the APPG is alive and we have the AGM next week which we will be emailing you about soon!
- Is there any traction using celebrities that some of you may have connected with your charities... a random thought but media might pick up?
- We were unable to register the APPG before going on furlough, but the APPG still can exist without being on the official register. However next week we will formally register the group again!
- Would be nice to have stories from healthcare professionals as well, especially if they are in plain English :)
- Coordination of care (CONCORD) is a current priority (which rather sums up what we are all about ultimately).
- The Covid-19 thing is interesting. My child may not be able to take a particular form of the vaccine because of her specific genetic condition.
- Social media influencers would be great to support next year's campaign.
- M4RD brought up an interesting point about how rare disease is hidden. This is something which was highlighted during Covid shielding. I can remember my elderly neighbour glaring when my husband got a priority shopping slot. Hidden transplant!
- At one time cancer was a rare disease. Then Breast Cancer raised the profile, and then others so that even testicular cancer is talked about openly let alone vaginal cancers
- I think success looks like engagement from the communities we represent. The Film Festival was great in doing that - over 15,000 people watched our film about Aortic Dissection - it would have taken us years to achieve that normally. We should think carefully about engagement metrics for everything we do online, so that we know how successful we've been.
- Nice insight into the strategy. Clearly Covid-19 is creating an opportunity for more people to the rare disease experience and understand the issues around research and treatment. So this year can really push the wider understanding, and move more into caring.

- Is there a way of getting some 'media partners' from larger organisations e.g. universities. Maybe we could use the researchers in our rare conditions to tunnel some messaging through to university social media channels etc.
- Do we need to think of a non-traditional route of making social media drive press not the other way around? Remember to make everything you do social media friendly. Short, snappy videos for example
- I am happy to be involved in any way I can to raise awareness of rare diseases, including in BAME communities.