

# COMMUNITY CHECK-IN NOTES

Tuesday 22 September: Return of NHS Clinics

## Organisations represented:

- Alex TLC
- Alström Syndrome UK
- Behcet's UK
- Duchenne Family Support Group
- Hereditary Spastic Paraplegia Group
- Hypermobility Syndromes Association
- The MPS Society
- Muscular Dystrophy UK
- Pitt Hopkins UK
- PKD Charity
- Primary Immunodeficiency UK
- Ring20 Research and Support UK
- Same but Different
- SWAN UK
- 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
- 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

JS welcomes all in attendance and notes that this meeting will focus on clinics returning and welcomes two guests – Fiona Marley (Head of Highly Specialised Commissioning at NHS England) and Dr Ros Quinlivan (Queens Square - Neuromuscular Consultant).

## Presentation from Fiona Marley

- Undertook consultation to understand family and carer experience of those accessing virtual rare disease clinics. Calls took place in June.
- People liked face to face clinics – notes the social interaction and informal chats that don't happen virtually.

Genetic Alliance UK

[contactus@geneticalliance.org.uk](mailto:contactus@geneticalliance.org.uk)  
[www.geneticalliance.org.uk](http://www.geneticalliance.org.uk)

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

#### What has worked well:

- Video calls can determine how urgent a case is
- Virtual MDT (multidisciplinary team) follow ups are happening
- Technology is helpful with some platforms allowing one member of the MDT team and the patient to go to separate 'room' if necessary
- Allows for wrap around care

#### Not working well:

- Restricted diagnosis
- Limited assessment of deterioration
- Challenging for those with sensory issues and neurological impairment
- Challenge for very small children
- Some patients would rather wait to be seen face to face
- Local teams don't have specialist experience and expertise to manage patients and need support from the RD services on management

#### Opportunities for transformation:

- Diagnosis, assessment and care - perhaps there are some pre-diagnosis things that can be done?
- Limit journey times and distances
- 'Hospital at home' makes equipment available at home, drug delivery, home blood testing etc.
- Care coordination of tests and prep for sessions
- Support to patients and families

#### **Presentation from Ros Quinlivan**

- Patients they see were generally shielding during lockdown so patients did not want to come to hospital
- Throughout lockdown did consultations by telephone – most patients found this helpful especially that they didn't have to travel as often long distances and they didn't have to use public transport
- Video consultations have been excellent – almost as good as face-to-face for patients they already know. Slightly more problematic for new patients
- For patients unable to travel they had been arranging genetic testing locally by sending packs to patients
- Notes concerns about sensory impairments and for those patients who have difficulties vocalising.
- Using other technology, for example patients' smart phones, to do things such as record the steps that they are taking has been beneficial
- 12-minute walking test now replaced by steps recorded on phone (JS notes that patients have been asking for this for a long time)
- For very vulnerable patients, the optimum is an overnight stay (on a green pathway for covid) with a follow up by telephone
- Notes limited capacity
- Sometimes technology can be temperamental and this causes problems including overrunning clinics

- Sometimes patients do not seem to be clear that these are clinic appointments and they might be in their car or in the supermarket - notes that maybe patients have to adjust to virtual clinics too.

### **Discussion:**

- Participant notes lack of technology for some families, especially disadvantaged families and that videos only on mobile phones are limited. Asks if there are discussions about how to provide this technology .
- FM says conversations are happening and recognises the value of ensuring proper technology and cost savings/redistribution from travel costs.
- JS raises undetected deterioration and asks about how this is acknowledged?
- RQ says trying to get round this by annual inpatient sessions and says that if you ask the right questions, you can also identify this. Notes that often, even if there is deterioration there is little that can be done, but being able to see people at home means can identify help/support that is needed. Notes much harder with the deteriorations you can't see, for example respiratory tests. Says work underway to look at home sleep service, but will take time and some tests, such as for the heart, will always require patients to attend clinics.
- Participant asks about GDPR issues with patients who have very limited or no sight as they aren't able to receive notes/letters by email due to GDPR but this means someone else has to have access to their personal note. Notes that if notes go to patients by email (pdf) patients can use screen readers to receive their notes.
- FM says first she has heard that hospitals won't send notes by email and will raise this.
- RQ says at the hospital she works at there is a consent form for patients to sign to say that patients want access by email.
- JS asks whether there are any ways we can formally establish the role of third sector in virtual clinics.
- FM says there are some cases where third sector organisations are involved but there is scope to develop this further.
- RQ highlights the positive experience of a support group they used to have that would meet (young people) with a limited attendance, since moving to zoom this has increased.
- Participant notes that pre-Covid she was about to join clinics to offer support but with Covid-19 pandemic this has been stopped as she can no longer attend due to restrictions.
- Participant notes that online services are helpful, but nothing beats face to face for providing support.
- JS asks about transition services (child to adult)
- RQ notes this has not been easy and is currently being done by zoom clinics.
- Participant notes that for some there has been a pause in transition and young people are staying in children's services for now. Also notes that there is an opportunity for families to get together virtually the day before clinic day.

- Participant knows of some issues where people are lost in the system, and this has been made more complicated by Covid.
- RQ explains the importance of transition nurses, but also explains the challenges of financing such a role, especially as a result of Covid-19.
- RQ says that transition funding always seems to fall through the net.
- FM notes she will feed this back.
- Participant notes the need for care coordinator is needed now more than ever.
  
- JS thanks FM and RQ for input and notes the valuable discussion.
  
- JS reminds that next week we will be talking about genomics across the UK.
  
- Participant asks whether we could have a discussion about shielding again. Notes that children were due to come off the shielding list, but families are unhappy about this.
- Participant shares this concern.
- Participant supports this too.
- Participant raises the need for consistency across the UK for guidelines.
  
- JS thanks Duchenne Family Support Group for making the link with RQ.