Cross Party Group on Rare, Genetic and Undiagnosed Conditions
Committee Room 6, Scottish Parliament
Tuesday 5th February 2019
6pm-8pm

Minutes of Meeting

- **Welcome and Introductions**

  Bob Doris MSP (Chair) welcomed all in attendance. John Scott MSP and Mark McDonald MSP were in attendance.

  Apologies had been received from Miles Briggs MSP and Anas Sarwar MSP.

- **European Collaboration for Rare Diseases - the future of European Reference Networks**

  Bob Doris MSP introduced the theme for the meeting. European Reference Networks (ERNs) connect patients, clinicians and researchers across Europe. They allow knowledge and expertise about rare diseases to be shared across Europe; providing patients with access to diagnosis and transformative care, without the burden of long-distance travel. ERNs enable researchers to engage rare disease patients across Europe to support clinical trials — offering families hope that an effective treatment, or even a cure, will be developed for their rare condition.
  At present the UK Government and the EU have not agreed on a withdrawal procedure that protects the UK's ability to continue to be involved in ERNs. Without continued involvement of the UK, the capacity of ERNs will be diminished and networks risk falling short of their ambition to raise standards and equity in rare disease care across the EU. Professor Mossey provided a short presentation explaining the background of ERNs and the value to patients with rare conditions in Scotland, citing examples of craniofacial anomalies and cleft lip and palate. Professor Mossey explained that there is tremendous potential within ERNs for rare disease research and that many aspects of the EU research into rare diseases had been world leading, driving standards of care for patients. With regards to the UK's (and Scotland's) participation in ERNs going forward, Professor Mossey explained that clinicians in Scotland and the rest of the UK had already been informed that they would be prohibited from participating in, and benefiting from the data collected by, ERNs from 29 March 2019.
  Professor Mossey explained that potential implications of being removed from ERNS include reduced access to the best diagnostic and surgical expertise, that the quality of patient care will suffer, potentially resulting in patients dying, the introduction of inequalities, the UK being unable to take advantage of research collaboration and unable to contribute/benefit from innovation. Professor Mossey also cited the potential cost implications of duplication of facilities and efforts and ensuring there was sufficient expertise in the UK. Professor Berg echoed the comments made by Professor Mossey and explained that a large axe had fallen, meaning that no patient data will be accepted by the EU after 29 March 2019 and that he would no longer be able to seek diagnostic expertise for his patients through the ERNs which would be damaging for UK patients. Professor Berg also explained that there were wider implications for the UK's research community after Brexit as EU funding has a special place in research, for example in the case of

duchenne muscular dystrophy, that patients will not be able to access. Professor Berg explained that cross-Europe collaboration can not be replaced by UK grants. Grants, such as those from the MHRA, will not provide the same mechanisms for cross border collaboration.

Cross Party Group members were invited to share their own experiences and thoughts on this issue. It was noted that patients with rare diseases in Scotland would lose out on the value of ERNs and other European research programmes. This was considered to be extremely detrimental to the outcomes of patients in Scotland and also patients in other parts of the UK and EU who would lose out on the wealth of clinical expertise available in Scotland. It was also noted that this would likely have a significant impact on Scotland's life sciences economy and that this would be in addition to concerns over medicine availability and regulation.

Mark McDonald MSP shared feedback from his meeting with Genetic Alliance UK and the Cabinet Secretary for Government Business and Constitutional Affairs, explaining that whilst it was the responsibility of Westminster to ensure appropriate consideration and planning for ERNs was undertaken, the Scottish Government was aware of this issue and had written to the Department of Health to establish the latest position on ERNs and raise concerns about Scotland's future involvement in the programme. It was also noted that it may be possible to negotiate future collaboration with ERNs for Scotland and that this was a matter that should be given consideration.

Discussion also centred on raising awareness of this matter, with the recognition that uncertainty relating to Brexit was covering a large number of important issues meaning ERNs were not necessarily receiving the attention that they deserve either in negotiations or in the press.

Natalie Frankish explained that Genetic Alliance UK were leading on a campaign to Protect ERNs which had received considerable support, and that all members of the Cross Party Group were encouraged to sign up to the campaign.

There was a unanimous consensus that more needed to be done to ensure European Reference Networks were protected post 29 March 2019. A number of actions were agreed:

Action - The CPG agreed to collaborate with the APPG on rare, genetic and undiagnosed condition to write to the Prime Minister, Health Secretary and Brexit Secretary (and other relevant MPs) in Westminster. The letter will ask what the current position on ERNs is and what will be done to protect Scotland, and the UK's, involvement after 29 March 2019. The CPG agreed not to take a position on Brexit in letter, only the importance of retaining ERNs. This letter will also be copied to the Scottish Government. The letter, once sent, would be circulated to CPG members for them to share with their own MSPs and MPs.

Action - Natalie Frankish will work with Scottish clinicians and patient groups to put together a short briefing, including case studies and circulate to the group.

Action - Natalie Frankish will contact CPG on Life Sciences to discuss possible joint work in this area.

Action - The CPG will consider what other steps it can take to raise the matter of ERNs in the Scottish Parliament and media.

- **Raising Awareness and Improving Understanding of Rare, Genetic and Undiagnosed Conditions**
  Follow discussion from the last session where we spoke about digital patient passports and the importance of raising awareness of rare, genetic and undiagnosed conditions within the clinical community. The CPG was invited to consider how to improve understanding, not just in the clinical community but also within social care and education.

  Mr John Wallace introduced his experience regarding the use of technology in the classroom to allow his son to continue his education whilst unwell. John explained that he had been fighting for over two years for his local council to provide an AV1 Inclusive Learning Technology, to allow his son to continue to participate in school when he is too unwell to physically attend class. Mr Wallace explained that the Council had not yet provided the technology due to complaint from the school Parent Council. Mr Wallace explained the various contraventions of the Equalities Act 2010 that had taken place and the apparent lack of awareness/understanding of the provisions of the Act.

  Others in attendance expressed concern about this matter and highlighted other examples of discrimination in education (and other environments). The lack of awareness of other equality legislation and policy, including the Race Equality Framework for Scotland was also raised. It was agreed that the Cross Party Group would consider this matter further.

  Actions agreed were:

  Action - It was agreed that the CPG would write to Edinburgh City Council and East Lothian Council to commend them on recognising the value of technology in supporting young people with rare, genetic and undiagnosed conditions to participate in education and to ask for them to share their learning and best practice advice with the Cross Party Group.

  Action - Natalie Frankish will identify relevant CPGs to consider whether there is scope to do a wider piece of work to consider how awareness of the Equalities Act 2010 and other relevant legislation is being raised.

- **Any Other Business**
  - The annual Rare Disease Day Parliamentary Reception will take place on Tuesday 5th March 2019 between 6pm and 8pm in the Scottish Parliament.
  - The CPG has been invited to collaborate with the Cross Party Group on Muscular Dystrophy on the issue of hospice and respite care. The CPG agreed that this would be a relevant issue to collaborate on and Natalie Frankish will take this forward with the Secretariat of the CPG on Muscular Dystrophy.

- **Date of Next Meeting**
  - The next meeting will include the AGM and will
  - take place on Tuesday 23rd April 2019 between 6pm and 8pm in Committee Room
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Attendance List CPG on Rare, Genetic and Undiagnosed Conditions Feb 2019

Bob Doris MSP	Chair
John Scott MSP	CPG Member
Mark McDonald MSP	MSP
Natalie Frankish	Genetic Alliance UK
Professor Peter Mossey	University of Dundee
Professor Jonathan Berg	University of Dundee, NHS Research Scotland
Professor Zosia Miedzybrodzka	University of Aberdeen
Karen Ritchie	Healthcare Improvement Scotland
John Wallace	NLRP12
Keir Wallace	NLRP12
Harriette Campbell	Sickle Cell & Thalassaemia Support Group
Edel Clough	Scottish PCD Committee
Sue Rees	UK PIPs (Scotland)
Arlene Smyth	TSSS
Marion Yakova	Office for Rare Conditions
Lynne Shields	Tuberous Sclerosis Association
Tracey Bowden	Pfizer UK
Catherine O'Hara	Behcet's UK
Hazel Mclachlan	Behcet's UK
Sam Hemmati	Sobi UK
Andrew Deans	NHS Lothian
Lynn Stewart	MyAware
Amy Comrie	EDS UK
Jenni Hampson	Kyowa Kirin