Cross Party Group on Rare, Genetic and Undiagnosed Conditions

Tuesday 3 December 2019

Committee Room 3, Scottish Parliament

1pm – 2.15pm

MINUTES (DRAFT)

- **Welcome and introductions**

Bob Doris MSP welcomed all in attendance and noted apologies received from Miles Briggs MSP, Arelene Smyth, Kirsten Patterson, Sue Rees, Rae McNairney and Hazel McLachlan.

- **Coordination of Care for Rare, Genetic and Undiagnosed Conditions**

It was noted that in previous meetings of the Cross Party Group, poor care coordination has been an underlying theme. Typically, patients and families living with rare, genetic and undiagnosed conditions experience having to attend multiple appointments, with multiple health professionals from different medical specialities, in different locations. For most, there is an absence of a dedicated care coordinator or a named contact.

Natalie Frankish explained that the Rare Disease Strategic Oversight Group would be considering care coordination as a key theme in the near future and suggested that the CPG generate suggestions and recommendations that can be shared with the group. Suggestions include:

- A "centre of excellence" or centre for Rare Diseases in Scotland. GOSH and the Birmingham's Centre for Rare Disease were cited as good examples that could or should be followed. It was noted that the Office for Rare Conditions in Glasgow was a model that could be replicated across Scotland to improve care coordination. Whilst a single centre was considered favourable due to Scotland's population size and the opportunity for clinical collaboration, it was also noted that such a model would require considerable funding investment and would not necessarily be able to recreate the model of those in England due to Scotland's population and geographical spread. A virtual centre model however, could be explored, and this would address the challenges of cost.
- There was overwhelming support for dedicated 'care coordinators' for rare conditions. The role of the specialist nurse was considered a model for this and previous initiatives such as the Single Gene Complex Needs Network were agreed to be a strong basis for developing this model. It was acknowledged that it would be possible to have a coordinator for all conditions (or indeed, that all patients would require one) but that a rare disease care coordinator could have a role in dealing with many conditions – recognising that nurses with a understanding of what it means to have a rare condition,

the information and support needs of families and how to appropriate support families to meet those needs was most important. Again, a significant challenge to this model is funding. Concern was raised that third sector funding would neither be reasonable or sustainable given the breadth of conditions that would be covered – sustainability of central, health board or government funding is also difficult to guarantee.
- There must be a willingness to embrace technology, both in the form of virtual meetings/appointments and through improved IT and patient held records.
- There was support for improved care pathways and care plans, with these being accessible to professionals and families. It was noted that the unpredictable nature of rare conditions often means care pathways may not be appropriate. It was also noted that care pathways must also include mental health care and support.

Andrew Deans raised the Alpha-1 policy document which outlined the importance of care coordination.

A parent raised concerns regarding poor integration between health and social care services and budgets – in particular raising the fact that for rare diseases, funding simply isn't available and families are not obtaining the appropriate services or care needed because there is a) a lack of understanding of rare conditions and the needs of families and b) there is no funding available through local authorities. The point was made that money was simply not allocated to rare diseases – that the staff in the NHS and social care services were under considerable pressure to deliver services with little funding. It was noted that this issue should be raised with the Cabinet Secretary for Health and Wellbeing. The parent who raised this concern, for which there was much agreement from other CPG members, was advised of the public petitions process.

Actions:

- Natalie Frankish to write a short report on the recommendations for care coordination and share with the Rare Disease Strategic Oversight Group.
- The CPG will send a letter to the Cabinet Secretary for Health and Wellbeing to raise a question regarding the available budgets for rare disease services and to enquire as to the role out of the joint health and social care budgets to children's services.

- **AOB**

The Rare Disease Day Parliamentary Reception will take place in the Scottish Parliament on Wednesday 4 March 2020.

Bob Doris MSP	Convener
Mark McDonald MSP	MSP Member
Natalie Frankish	Genetic Alliance UK
John Miller	Action Duchenne
John Wallace	NOPR2
Gill Dickson	PSP Association
Martina Rodie	Office for Rare Conditions (Glasgow)
Elisabeth Hunter	ROHHAD
Layla Robinson	Kyowa Kirin
Lesley Loeliger	PNH Scotland
Dan Farthing Sykes	Haemophilia Scotland
Amy Comrie	EDS UK
Andrew Deans	NHS Lothian
Harriette Campbell	Sickle Cell Support Group
Lynn Stewart	MyAware