Cross Party Group on Rare, Genetic and Undiagnosed Conditions

Tuesday 17th April 2018

Committee Room 6 – 1pm to 2.00pm

AGM & CPG Meeting

Minutes (DRAFT)

- **Welcome**
  Apologies were received from Miles Briggs, Arlene Smyth, Sandra Thoms.

- **AGM Business**

Election of Office Bearers: Bob Doris MSP was elected Convener of the Cross Party Group, John Scott was nominated and elected Deputy Convener. Natalie Frankish (Genetic Alliance UK) was nominated and elected Secretariat and Treasurer.

Treasurer's Report: The CPG does not charge a subscription fee, a decision made at the first meeting. Genetic Alliance UK provide secretariat for the Cross Party Group, this 'material' support is costed at approximately £4,066. Genetic Alliance UK also provide the funds to cover catering of the CPG meetings, in 2017/18 this totalled £484.68

Annual Review: In the 2017/18 session the CPG has focused on care coordination and specialist nursing, the implementation of Montgomery Review recommendations and the implementation of the Scottish Plan for Rare Diseases. The CPG has invited guests including the Chief Nursing Officer and the Clinical Priorities Team of the Scottish Government to attend meetings to hear from patients, patient groups and others with an interest in rare diseases. The CPG has also engaged in written communication with the Cabinet Secretary on various matters important to the group. It was noted that MSP attendance could be better and it was agreed that future meetings will be on a Tuesday evening in effort to increase attendance. Work will also be undertaken to increase MSP and non-MSP membership for the 2018/19 session.

- **CPG Meeting**

Review of minutes from last meeting and matters arising - the minutes of the last meeting were agreed.

Priorities for the CPG - the remainder of the meeting centred on the key topics for future work/meetings and priorities for the CPG. These included:

- **Linking with the framework for disabled children agenda -** this was agreed as a priority topic. The team from the Scottish Government and the Children's Commissioner will be invited to a future meeting.
- **Access to Specialist Nursing -** this work will continue, with a proposal of a care coordinator/specialist nursing service to be drafted for discussion at a future meeting. There is a need to explore avenues for funding of this service, which may require further engagement with the Cabinet Secretary on this matter.

- **Access to New Medicines -** the implementation of the Montgomery Review recommendations will be revisited after summer recess, to explore the implementation of the changes expected to be announced in Spring 2018.
- **Data and Access to Information -** there was detailed discussion about the difficulties in patients being able to access and hold their own patient records. There was frustration that patients with complex and rare, genetic and undiagnosed conditions are still required to provide an account and explanation of their condition to each health professional they meet. It was noted that there is often positive stories of work being undertaken to improve data collection and access to health information, but very few stories of implementation and success. It was noted that data and e-health is integral to the implementation of the UK Strategy for Rare Diseases and the Scottish Plan for Rare Diseases. This will be a key theme for a future meeting.
- **Raising the profile of rare conditions within the clinical community -** it was noted that knowledge and understanding of rare conditions amongst primary care providers (and in some secondary/tertiary services) was lacking. Whilst the challenge of rare diseases is that it is not possible for all primary care providers to know about all rare conditions, it was agreed more had to be done to raise the knowledge and understanding of rare conditions amongst these services. It was agreed that at a future meeting representatives of the royal colleges will be invited to participate in discussions regarding how best to raise the profile of rare conditions within the clinical community.
- **Other priorities:**
    - It was noted that there needs to be an active effort to engage with a larger number of MSPs and encourage membership and attendance of the CPG. Natalie will correspond with non-MSP members to determine the best way in which to do this.
    - It was agreed that many of the key topics identified by the CPG are underpinned by commitments in the UK Strategy for Rare Diseases and the Scottish Plan for Rare Disease - it was agreed that representatives of the Scottish Government's Clinical Priorities Team will be invited to attend all future meetings as an observer.

ACTIONS:

- Natalie to make arrangements for the future programme of CPG meetings
- Natalie to communicate with non-MSP members by email to discuss how best to increase attendance at meetings
- Natalie to invite Scottish Government's Clinical Priorities Team to attend future meetings as an observer.

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Attendees

Lynn Stewart	MyAware	Attendee
Harriette Campbell	Sickle Cell Thalassaemia Support Group	Attendee
Michelle Conway	Alexion	Attendee
Bob Doris (Chair)	MSP	Attendee
Hannah Van Hove	Office for Rare Conditions, Glasgow	Attendee
Liz Dougan	Office for Rare Conditions, Glasgow	Attendee
Natalie Frankish (Secretariat)	Genetic Alliance UK	Attendee
Rae McNairney	PID UK	Attendee
Lesley Loeliger	PNH Scotland	Attendee
John Miller	Action Duchenne	Attendee
John Scott MSP	MSP	Attendee
Salena Begley MBE	Family Fund	Attendee
Amy Comrie	EDS and HSD Awareness Steering Group	Attendee
Hazel McLachlan	Bechets Syndrome Society	Attendee
Sue Rees	UK PIPS	Attendee