

Cross Party Group on Rare Diseases

27th October 2015 (5.30pm - 7.30pm)

The Scottish Parliament

Minutes

- **Welcome and introductions**

Malcolm Chisholm welcomed all in attendance, invited members to introduce themselves.

- **Update of Access to New Medicines Fund**

Kathryn Fergusson, Head of Medicines at the Scottish Government attended the meeting to provide an update on the New Medicines Fund, the SMC Review and an introduction to the Peer Approved Clinical System.

Kathryn explained that the New Medicines Fund had been increased to £90million. The fund is the redistribution of Scotland's share of the Pharmaceutical Price Regulation Scheme (PPRS) rebate. The fund is allocated, proportionally, to Health Boards to administer based on need and Health Boards. The Scottish Government will hold a small amount of funds centrally to support any health boards which may require additional funding. Health Boards have been advised to contact Scottish Government immediately should they have concerns about funding.

An independent review of the progress being made under the new arrangements for orphan, ultra-orphan and end of life treatments at Scottish Medicines Consortium is expected to be announced imminently. Kathryn shared a document with details of the draft scope of the review.

Kathryn explained that the transition from Individual Patient Treatment Requests (IPTRs) to Peer Approved Clinical Systems (PACS) has been delayed to allow a pilot scheme to take place in Greater Glasgow and Clyde. It was noted that there had been a significant increase in the number of successful IPTRs since the removal of exceptionality criteria.

- **Specialist Nursing for Rare Diseases – proposal for a CPG report**

Natalie explained that there had been a lot of interest from members on the topic of specialist nurses for rare disease. At the previous meeting the group had heard testimonies from campaigners for sickle cell and had a

presentation on the Single Gene Complex Needs Network. It was noted that the recent announcement of the £2.5m Specialist Nursing Fund and the associated Scottish Government review was welcome, but no patient groups in attendance had been invited to contribute their views on how the fund should be allocated.

It was agreed that consultation with patient groups should be undertaken and a report outlining need for specialist nursing in rare diseases be developed. It was noted that it would take a while to establish evidence for this report, and a number of members of the group agreed to assist in the reports development. Natalie noted that this would be a topic returned to at future meetings.

- **The Named Person Policy**

Concern was raised about the implications of the named person policy by a member of the group, specifically that the legislation could lead to the 'named person' making decisions on a child's clinical care without the permission of a parent/guardian/ It was noted that many of the members in attendance were unaware of this policy, however those that were knowledgeable about the process expressed confidence in the policy and explained that this particular concern was not in line with the intention of the policy.

It was agreed that Natalie Frankish would investigate possible opportunities for further training on the named person policy.

- **Update from Members**

It was noted that the Rare Disease Parliamentary Reception would be held on Tuesday 1st March 2016.