

Cross Party Group on Rare Diseases
Scottish Parliament
Tuesday 17th June 2014
5.30pm-7pm

Minutes

1. Introductions and apologies

Bob Doris welcomed those in attendance and invited those around the table to introduce themselves.

2. Minutes of previous meeting

The minutes of the previous meeting were approved.

3. Scottish plan for rare diseases – Elizabeth Porterfield, Scottish Government

Apologies were noted from Elizabeth Porterfield who was unfortunately unable to make the meeting. It was noted that the Scottish Plan for Rare Diseases was awaiting Ministerial sign off and was expected to be published in the summer.

4. The role of National Services Division – Deirdre Evans, National Services Division

Deirdre Evans, Director of National Services Division, provided a presentation to explain the role of National Services Division and the role of National Managed Clinical Networks in Scotland.

The presentation can be found [here](#).

5. The Scottish Muscle Network – Marina Di Marco

Marina Di Marco, Lead Clinician for The Scottish Muscle Network (SMN), provided an introduction to the SMN and explained how a National Managed Network provides benefits to patients with a range of muscle disorders in Scotland.

The presentation can be found [here](#)

6. Scottish Paediatric & Adolescent Infection & Immunology Network – Vicki Price

Vicki Price, Clinical Nurse Specialist at the Children and Young Peoples Immunology Service in Glasgow, provided an overview of the Scottish Paediatric and Adolescent Infection and Immunology Network (SPAIIIN).

The presentation can be found [here](#)

7. Syndromes Without a Name – Lauren Roberts, SWAN UK

Lauren Roberts introduced SWAN UK, an initiative of the charity Genetic Alliance UK offering support and information to families of children with undiagnosed genetic conditions.

Approximately 6000 children a year are born with a genetic condition that is likely to remain undiagnosed. Lauren showed a short video highlighting what life is like for a child with an undiagnosed genetic condition and explained the challenges that often face SWAN families.

Swan UK family videos can be accessed [here](#) and more information on SWAN UK can be found at <http://undiagnosed.org.uk/>

8. AGM

- Bob Doris reflected on the success of the first year of the Cross Party Group on Rare Diseases, noting in particular the consistently high attendance rates and the extremely informative meetings. It was noted that the CPGs had covered a number of important topics over the year including; the Scottish plan for rare diseases, access to medicines, rare disease research and managed clinical networks. The input from high-profile speakers was also acknowledged and members were thanked for their valuable contributions to the discussions that had been had.
- Treasurers update –

Catering Costs	£154.62
Value of Secretariat Support	£5797.50
Total	£5,952.12

- Malcolm Chisholm and Bob Doris were returned as Co-Convenors for the 2014/15 session.
- Natalie Frankish (Genetic Alliance UK) was returned as Secretary and Treasurer for the 2014/15 session.