

Cross Party Group on Rare, Genetic and Undiagnosed Conditions - AGM

Tuesday 26 May 2020 (11am)

Zoom Meeting

Note of Meeting

- **Welcome**

Bob Doris MSP welcomed all to the virtual cross party group AGM.

- **Election of office bearers**

- Bob Doris MSP was returned as Co-Convenor
- Mark McDonald MSP was returned as Co-Convenor
- John Scott MSP to be offered opportunity to continue as Deputy Convenor
- Natalie Frankish (Genetic Alliance UK) was returned as Secretariat and Treasurer.

- **Treasurers Report**

The CPG outgoings totalled £491.40 for catering costs.
No subscription fee is charged.

- **AOB**

It was agreed that the zoom format had worked well for the meeting and that a future meeting (likely June) would be organised.

The CPGs work on care coordination is ongoing, although delayed as a result of the Covid-19 situation. Further work will be conducted by email and online forum, with a view to finalising and publishing a report at an appropriate date in the near future.

Attendees

Bob	Doris MSP	Convener
Mark	McDonald MSP	MSP member
Natalie	Frankish (Secretariat)	Genetic Alliance UK
Salena	Begley	Family Fund
Claire	Black	SWAN parent
Marion	Butchart	Novartis
Mike	Cain	HSP Support Group
Harriette	Campbell	Sickle Cell Support Group
Edel	Clough	PCD Family Support Group
Amy	Comrie	EDS UK
Michelle	Conway	
Andrew	Deans	NHS Lothian
Gill	Dickson	PSP Association
Rachael	Docherty	FOP Friends
Jenni	Hampson	Kyowa Kirin
Elisabeth	Hunter	ROHHAD Association
Pushpa	Hussain	Metabolic Support UK
Tanya	Jones	
Coreen	Kelday	Brittle Bone Society
Zoe	KM	Autoinflammatory Disease UK
Hazel	McLachlan	Behcet's UK
Rae	McNairney	
Stacey	McPherson	CHAMP1
Zosia	Miedzybrodzka	University of Aberdeen
John	Miller	Duchenne Muscular Dystrophy
Jodie	Mitchell Hyslop	Harper's Helpers
Ali	Murray	
Prince	Obike	Sickle Cell Support Group
Catherine	O'Hara	Behcet's UK
Karen	O'Hara	Alpha 1 UK
Martina	Rodie	Office for Rare Conditions
Tracey	Saunderson	On behalf of Emma Harper MSP
Laura	Smith	Children's Health Scotland
Arlene	Smyth	Turner Syndrome Support Society
1`Katie	Thurston-Smith	Pfizer
John	Wallace	Autoinflammatory UK NLRP12
Lindsay	Weaver	Metabolic Support UK
Alex	Whitteker	Haemophilia Scotland
Anne	Wilson	Children's Health Scotland