

Cross Party Group on Muscular Dystrophy meeting on 27th June 2018

Co-Conveners: Jackie Baillie MSP and Annie Wells MSP

Also attending:

Alison Johnstone MSP

Guests

Jonathan Kingsley, Muscular Dystrophy UK

John Miller, Action Duchenne

Oona Miller

Robbie Warner

Meeting summary

MSPs and guests introduce themselves.

AGM Business and re-election of officers conducted.

Muscular Dystrophy UK update:

- Spinraza latest developments in Scotland and England
- Update on new ultra-orphan medicines pathway and planned timelines

Discussion on priorities for the group for the forthcoming year:

- Fast Track to treatments
- Access to Spinraza
- Implementation of the new ultra-orphan medicines pathway
- Mental health and wellbeing
- Hospice provision and respite provision for children and adults
- Specialist multi-disciplinary care for adults

Meeting closes.