

Cross-Party Group on Epilepsy

29 November 2023 12:30-13:30

Minute

Present

MSPs

Alasdair Allan MSP- Convener
David Torrance MSP- Deputy Convener

Invited guests

Shubhanna Hussain-Ahmed

Non-MSP Group Members

Lesley Young
Pauline Stansfield
Andrew Lindsay
Derek Robertson
John Thomson
Audrey Noble
Susan Duncan
Andrena Hughes
Jan Campbell
Shirley Maxwell
Coleen Wilson
Scott Coyne
Lorna Forrest

Apologies

Elaine Collard
Lorraine MacKenzie
Christine Jeans

Agenda item 1- Welcome

Convener welcomed group to last meeting of year and thanked group for work it has done over the last year, especially around the highlighting men's health and epilepsy. Convener discussed opportunity for new year to present new way for CPG to operate. He passed on to Andrew Lindsay, representing CPG secretariat- Epilepsy Consortium, who discussed a new approach to CPG in new year including;

- New more focussed approach on specific issues facing epilepsy sector
- Less, but more focussed scheduled meetings- 2 a year
- More MSPs involved

There was general approval of proposed changes amongst those in attendance.

Agenda item 2- Epilepsy and Client Contributions in Non-Residential Care

Heard contributions from Lesslie Young (CEO, Epilepsy Scotland) and Shubhanna Hussain-Ahmed, (Partnership Development Officer, Coalition of Carers in Scotland) on the issues surrounding epilepsy and client contributions for those in non-residential care. Issues highlighted included patchwork nature of charging policies and rates across Scotland, lack of transparency of what local charging policies are, cost of living, shameful use of debt collectors and disability related expenditure.

Agenda item 3- Question and Answer session

Those in attendance discussed the issues raised in presentation in more detail. Following these discussions the CPG agreed that the secretariat would work with the Convener to develop some asks to be added to a letter sent to relevant Minister(s).

Agenda item 4- AOB

Several other issues were highlighted by those in attendance including:

- Sodium Valproate- how will Scottish Government support NHS Scotland in delivering on new guidelines being implemented by MHRA
- Medical Cannabis (Cannabis Oil)- Why is it still difficult to get access to on NHS? Is there scope for new Epilepsy Research Institute to do some work around this?
- Local Epilepsy Support Groups- Is there scope for CPG to use small local epilepsy support groups to help campaigning