

Cross Party Group on Multiple Sclerosis (MS)

Meeting Agenda

Tuesday 1st March 2016
6 pm – 8 pm
Scottish Parliament – CR4

1. Welcome and introductions

George Adam MSP, Convener

2. Actions from previous minutes

3. MS Society Manifesto – Get Loud for MS

Morna Simpkins, Scotland Director of MS Society, will talk through the MS Society manifesto for the Holyrood elections and how folk can get involved. There will be room for discussions of wider campaigns ahead of the election.

4. Research talk from Prof. Doreen McClurg and Dr Selina Doran

Prof McClurg and Dr Doran will introduce a presentation and Q and A on their clinical trial about neurogenic bowel dysfunction in MS.

5. Update from APPG on MS and Next Steps

Niall Sommerville, MS Society, will give an update on the work of the APPG on MS at Westminster and discuss ways in which the CPG can feed in.

6. Forward planning for CPG post-election

A discussion on re-convening the CPG post election

7. AOCB + Provisional Date of Next Meeting

Attendees:**MSP Members:**

George Adam MSP (Convenor)
Chic Brodie MSP

Other attendees:

Niall Sommerville, MS Society
Rebecca Duff, MS Society
Morna Simpkins, MS Society
Stacey Adam, Personal interest in MS
Merv Graham, Personal interest in MS
Carole Macartney, Chair of MS Therapy Centre Lothian
Jaqui Downs, MS Managed Clinical Network Manager, NHS Ayrshire
Dr Belinda Weller, Consultant Neurologist, NHS Lothian
Mairi O'Keefe, Chief Executive, Leuchie House
Prof. Doreen McClurg
Dr. Selina Doran
Iain Morrison, MS Revive
Judith MacSween, NHS Lothian
Marion Butchart, Novartis

Apologies:

Lewis MacDonald MSP
Mark McDonald MSP
John Finnie MSP
Elizabeth Quigley
Ruth Sumpter
Carly Gillespie

Minutes:

1. Welcome and Introductions

The Convenor, George Adam MSP, welcomed members and noted apologies.

2. Actions from previous minutes

George Adam MSP shared the letter he had received from the Scottish Govt regarding MS specialist nurses. Intimated he was happy to continue to press the Govt on this issue. Mhairi O'Keefe raised the delay at health board level in recruiting specialist nurses. George Adam noted this was a recurring issue.

George Adam noted response back from NHS Ayrshire and Arran regarding the ongoing neurologist issue. Jaquie Downs gave a further update and noted that a neurologist has been secured for 2 days per week and it's hoped that a neurologist will be in place permanently in June.

3. MS Society Manifesto – Get Loud For MS

Morna Simpkins introduced the MS Society 'Get Loud for MS' manifesto and talked through the key asks of election candidates. MS Society will be promoting their manifesto in the lead up to the election and looking for support from election candidates. Becky Duff agreed to share further information on MS incidence rates with members electronically, as highlighted in the manifesto.

The second ask in the manifesto relates to a stronger voice for people with MS in health and social care integration structures. This led to a wide ranging discussion on limited role the third sector has in integration at present. Alongside this are ongoing issues around the availability of respite care which were raised by Mhairi O'Keefe and Iain Morrison.

George Adam and Iain Morrison both suggested having a roundtable discussion with the Cab Sec for Health along with local authorities and delivery agents. The group will pick this up post-election.

Issues around the Carers Bill were raised, in particular there being no national standards introduced. Becky Duff noted the MS Society would be happy to be involved in any campaign others are running relating to carers.

4. Research talk from Prof. Doreen McClurg and Dr Selina Doran

Prof. Doreen McClurg and Dr Selina Doran gave a research and information presentation on continence issues for people with Multiple Sclerosis. This included information on the AMBER project that they are involved in. They also sought to

raise the profile of the 'It's Personal' toolkit. For more information contact Dr Selina Doran selina.doran@gcu.ac.uk

5. Update on the APPG on MS

Niall Sommerville provided an update on the work of the APPG on MS, the Westminster equivalent of the CPG on MS. He explained that they were using the APPG to carry out a review into employment support for people with MS. They are carrying out three evidence sessions between January and September looking at current out of work support, current in work support, and solutions to problems with employment support. Alongside this they are seeking written submissions from interested organisations into the review. Following the completion of the review a report will be produced and launched towards the end of 2016. This will form part of the MS Society's MS: Enough campaign.

The group agreed it would be good to feed into the review in order to give a Scottish perspective on available support. It would also be the first time a CPG and APPG had worked together on a piece of work, providing a unique opportunity for the group. The CPG will look to use their first meeting of the next Parliament as an evidence session to shape their response to review. Niall Sommerville will speak to George Adam to discuss how best to take this forward.

6. Forward Planning for CPG post-election

The group discussed topics they wished to look at following the election. Alongside the session on the employment review it was agreed that a session on health and social care integration was required towards the end of the year. Other suggestions included looking at the national managed clinical network for MS. Niall Sommerville will pick up ideas with George Adam if he is re-elected.

7. A.O.C.B

Belinda Weller raised the issue of access to Alemtuzumab (Lemtrada) in Edinburgh and the issues this is causing. Becky Duff noted this had been raised by others as well and that the MS Society will look into this.

Iain Morrison talked about the positive changes happening at Revive MS Support and that they are hoping to get sign off on new larger premises in the very near future. This should allow them to support even more people effectively. He noted that a withdrawal of statutory services has led to an increase in service users. He also talked about an increased interest in e-health.

Marion Butchart asked about the review of the NNAG. Becky Duff talked about the proposed changes and agreed to circulate the related letter.

Meeting closed at 20:03. No date was agreed for the next meeting due to the election but it was agreed that the group would look to reconvene in June if possible.