

## **Cross Party Group on Multiple Sclerosis (MS)**

**Draft Minutes**  
**Tuesday 24<sup>th</sup> November 2015**  
**6 pm – 8 pm**  
**Scottish Parliament – TG 20/21**

**1. Welcome and introductions**

George Adam MSP, Convener

**2. Actions from previous minutes**

**3. AGM / Election of Office Bearers**

Election of Convenor, Vice-Convenor and Secretariat

**4. Update from Mairi O'Keefe, Leuchie House**

'Where we are now and where we're going'

**5. Early Treatment**

Dr Belinda Weller explains new scientific consensus that changes the way relapsing forms of MS should be treated

**6. Impact of integration**

Edinburgh Therapy Centre on the impact of integration on service commissioning.

**7. APPG for MS**

Update from the MS Society Scotland on the work of the All-Party Parliamentary Group for MS at Westminster and its upcoming inquiry

**8. CPG on MS - Workplan 2016**

Discussion on possible topics for the CPG Workplan for 2016

**9. AOCB and Date of Next Meeting**

**Attendees:****MSP Members:**

George Adam MSP (Convenor)  
Nanette Milne MSP  
Chic Brodie MSP

**Other attendees:**

Stacey Adam, Personal interest in MS  
Merv Graham, Personal interest in MS  
Harry Travers, Personal interest in MS  
Carole Macartney, Chair of MS Therapy Centre Lothian  
Jaqui Downs, MS Managed Clinical Network Manager, NHS Ayrshire  
Martine Sinclair, Neurology Business Manager, Biogen Idec – ABPI rep  
Nigel Graham, Merek Group  
Dr Belinda Weller, Consultant Neurologist, NHS Lothian  
Mairi O’Keefe, Chief Executive, Leuchie House  
Aislinn Lunt, MS Society  
Morna Simpkins, MS Society  
Niall Sommerville, MS Society

**Apologies:**

Lewi MacDonald MSP  
Elizabeth Quigley, Personal interest in MS  
Iain Morrison, Chief Executive, Revive MS Support  
Dr Ruth Sumpter, Consultant Clinical Psychologist  
Judith McSween, Speech and Language Therapist

# Minutes

## 1. Welcome and Introductions

The Convenor welcomed attendees and accepted apologies.

## 2. Minute of previous meeting / Matters arising

George Adam MSP noted he had received a response back from NHS Ayrshire and Arran regarding the previous letter. Noted they are having troubles filling the position but are actively trying to recruit at present. Jaqui Downs explained the current situation in Ayrshire and Arran, including interim arrangements. Carole Macartney added that workforce shortages nationally had been raised elsewhere and that it is clearly an issue.

**Action:** Chic Brodie already has a meeting arranged with John Burns at NHS A+A in the near future and is happy to raise this issue whilst there. Aislinn Lunt will forward Chic Brodie the previous correspondence and a briefing on the issue. George Adam agreed to write to the Scottish Government on behalf of the CPG and also raise with the Parliamentary Liaison Officer for Health.

## 3. AGM / Election of Office Bearers

The following were elected by acclaim as office bearers for the CPG on MS:

Convenor – George Adam MSP

Vice Convenor – Lewis MacDonald MSP

Secretariat – MS Society

## 4. Update from Mairi O'Keefe, Leuchie House

Mairi O'Keefe talked about the work of Leuchie House, a facility which offers quality respite breaks with 24-hour nursing care in a non-clinical country house setting. Mairi gave an oversight of the services and activities Leuchie House delivers and their vision and aspirations over coming years.

## 5. Early Treatment

Dr Belinda Weller talked of the new scientific consensus around the way relapsing forms of MS should be treated. Noted that the key is to engage in a dialogue with people with MS early to inform them of their options and encourage decisions to be made. Relapses are the tip of the iceberg so we can't leave dialogue until this point. There's a need for consistent and ongoing monitoring along with discussions on benefits and risks of treatments. Aislinn Lunt talked of the work the MS Society had undertaken around the 'Time to Act' campaign and is keen to receive information on where people feel monitoring process and information being given is not up to date.

The issue of shortages of MS nurses was raised with anecdotal evidence of gaps in service across Scotland.

**Action:** George Adam MSP agreed to write on behalf of the CPG to the Cabinet Secretary for Health, Wellbeing and Sport to get an update on specialist MS nurses.

## **6. Impact of Integration**

Carole Macartney introduced the topic and gave an example from the Gateway project in Lothian and the issues they've had around funding following the integration of health and social care. Noted that there is concern that a range of good services are being squeezed out due to health and social care integration.

Discussion ensued on the integration process and in particular the experiences of the third sector within this process which had been largely negative. Concern was raised that the third sector had been side-lined in the process. CPG members raised the possibility of running a campaign on integration using examples of where local services had been lost during the integration process. In acting as the CPG this may take pressure off individual organisations who may feel unable to campaign due to local relationships.

**Action:** CPG to work with George Adam MSP on the possibility of a motion and members debate to raise some of these issues. MS Society will work to create a campaign plan on behalf of the group. CPG members to provide examples of where third sector provision has been hit by integration or where the third sector has stepped in to save local services.

## **7. APPG**

Aislinn Lunt talked about changes to the membership of the All Party Parliamentary Group (APPG) for MS at Westminster and their workplan for the upcoming year. Noted that there is significant opportunities for joint-working between the CPG and APPG in 2016. The Northern Ireland Assembly has recently set up an APG (All Party group) and this year will focus on MS nurses and waiting lists.

## **8. CPG Workplan**

The CPG had a brief discussion on a workplan for 2016. A number of suggestions were made, utilising the 'MS Enough' document as a starting point. Some of the suggestions were as follows:

- MS Enough campaign
- Navigating welfare changes / Devolution of welfare / PIP
- Arranging MSP visits to MS services
- Health and Social Care Integration
- Social isolation
- Access to drugs
- Carers Bill / Carers Week
- Possible campaign on getting SIGN guidelines for MS

MS Society will pull together a draft workplan and circulate to members. This will be subject to change following the 2016 Holyrood elections.

## **9. A.O.C.B + Date of next meeting**

George Adam MSP thanked Aislinn Lunt on behalf of the CPG for her work as Secretariat for the CPG.

The date of the next meeting was provisionally set as Tuesday 1<sup>st</sup> March 2016.

Meeting closed at 8:05pm