

**Cross Party Group on MS
Minutes of meeting**

Date Wednesday 5 February 2014

Time 18:00 – 19:00

Venue TG 20-21, Scottish Parliament

Agenda

Introduction and welcome from George Adam MSP, Convener

Lottery of treatment and care – key issues and opportunities
(Becky Duff, MS Society)

Draft CPG workplan for 2014 (George Adam MSP)

AOCB

Date of next meeting

Attendees

MSP Members:

George Adam MSP (Convener)
Lewis MacDonald MSP (Vice Convener)
Neil Findlay MSP
John Finnie MSP
Jim Hume MSP

Other attendees:

Iain Morrison	Chief Executive, MS Revive Support
Jenny Preston	Consultant Occupational Therapist, NHS Ayrshire and Arran
Duane Patterson	MS Specialist Social Worker, Dundee Social Work Department
Cat Johnson	Personal interest in MS
Merv Graham	Personal interest in MS
Andrew Johnston	Health Board Vice Chair, Dumfries and Galloway NHS
Dr Belinda Weller	Consultant Neurologist, NHS Lothian
Judith McSween	Speech and Language Therapist, and personal interest in MS
Carole Macartney	Chair, MS Therapy Centre Lothian
Sarah Richard	Policy, Press and Campaigns Manager, MS Society
Becky Duff	Head of Policy and Communications, MS Society
Marion Butchart	Government Affairs Manager Scotland, Novartis - ABPI rep
Martine Sinclair	Neurology Business Manager, Biogen Idec - ABPI rep
Karen Swan	Market Access and Government Affairs, Genzyme – EMIG rep
Simon Coates-Walker	Head of Pharmaceuticals, Consilient Health Ltd – EMIG rep
Elizabeth Quigley	Personal interest in MS
Fiona Burns	Personal interest in MS
Mairi O'Keefe	Chief Executive, Leuchie House

Apologies:

Nanette Milne MSP	
Bob Doris MSP	
Anne Stewart	MS Specialist Nurse, NHS Highland
Gareth Marr	Personal interest in MS
Dr Stewart Donald	Consultant in Rehab Medicine, NHS Lothian
Moira Flett	MS Specialist Nurse, NHS Orkney
Carly Gillespie	MS Specialist Nurse, NHS Greater Glasgow and Clyde

1 Introduction and welcome from George Adam MSP, Convener

Mr Adam noted that this is the first meeting of the CPG on MS and that the aim is to consider and agree a workplan for the year ahead. He noted that he was pleased to see the CPG on MS established and the high level of support for the Group. He referred to a shared intention to work together to raise the profile of MS and deliver change on key issues affecting the MS community in Scotland. Mr Adam mentioned that he would like to see the annual MS Week used as an opportunity to reflect on progress made by the CPG over the preceding year as well as being the focal point of awareness-raising. Attendees agreed that it is important for the CPG not to be a 'talking-shop' and for the CPG to work within a very outcome-focused workplan.

2 Lottery of treatment and care – key issues and opportunities (Becky Duff, MS Society)

Becky Duff, Head of Policy and Communications at the MS Society presented findings from the MS Society's *My MS My Needs* research. This research was undertaken in 2012 and involved a survey of 10,000 people with MS across the UK on their experiences of health, social care, employment and other aspects of living with MS. The findings were first reported in 2013 in the MS Society's report *A Lottery of Treatment and Care: MS Services across Scotland and the UK*.

One of the findings Becky highlighted was that only a third of eligible people are taking a SMC-approved disease-modifying medicine (of the seven approved at the time of the survey). She noted that while there were likely to be multiple factors behind this, such low prescribing raised serious concerns that there are people who aren't benefitting from treatment because of unnecessary barriers. With four new medicines being reviewed by the SMC this year, she noted that the MS Society's view that access to medicines is a priority area to address.

Becky also noted the finding that only 2% of people in the survey were taking a licensed symptom management treatment. She mentioned that these are not SMC approved and that very few Individual Patient Treatment Requests are being approved. The MS Society added that it believed that patients should not have to rely on the IPTR route to access licensed medicines and that they would like to see these medicines nationally-reviewed and approved by the SMC.

Findings were also presented on the high number of people with MS in Scotland who rely on disability benefits, and subsequent research which shows that welfare reform changes were causing many people with MS significant anxiety about how they will manage their condition in the future.

She referred to data that showed that three quarters of people with MS of working age are not in employment, commenting that this is the converse of the general working age population where three quarters are in work.

Moving on to the range of health and social care services that many people with MS will need to access with varying degrees of frequency and urgency, the MS Society's research found that a substantial number of people felt unable to access the services they needed – from one in five unable to access a consultant or nurse to four in ten not getting the emotional support they need.

Becky also noted that 7 in 10 people with MS rely on family and friends for unpaid care, support and assistance; while the survey only targeted those with a MS diagnosis other research shows that unpaid carers and family members have their own unmet need in terms of support.

Becky concluded by noting that there are some positive policy and legislative opportunities ahead to leverage, for example carers legislation, and health and social care integration; and that this Group can be key to leading change and improvement.

3 Draft CPG workplan for 2014 (George Adam MSP)

George Adam introduced the draft workplan which had been circulated in advance with the agenda and asked for comments with the aim of agreeing the final workplan after the discussion.

There was general support for the workplan, the themes proposed for 2014 and the suggestions for actions and activities in between meetings. Comments and discussion points included:

The role of the voluntary sector should be incorporated within the objectives section. Carers and family members should also be formally acknowledged up front in the workplan.

As well as the issues presented on earlier, attendees noted that there are further geographic inequalities in access to chronic pain services, funding for respite care, and access to neuro-psychiatry. There are also inconsistencies in aids and adaptations available through social work departments. The Group has a role to look into all these areas of inequality.

The Group needs to make sure that it takes a holistic approach and does not ignore the needs of people for whom, for example, there are no disease-modifying treatments but for whom other care, services and self-management were vital.

Information is a major issue for people with all types of MS, despite acknowledging improvements over the years. There are still major barriers even in knowing who to contact and what services and support to expect or ask for.

It was identified that there are problems with people slipping through the net after diagnosis. Attendees felt that despite there being a Neurological Standard to make sure that people with MS were being offered a review with a specialist at least every 12 months, this was not happening for a lot of people.

There was discussion around the role of the CPG in sharing and promoting best practice. An example was given of the Dundee MDT which includes Scotland's only Specialist Social Worker. Duane Patterson who holds that role agreed to present on this topic at a future CPG meeting.

In relation to health and social care integration, Andrew Johnston, Vice Chair of NHS Dumfries and Galloway commented that integration must ensure the availability and retention of specialist services rather than their dilution. He added that MS is a prime example of where integration must encompass all adults not just older adults.

Iain Morrison raised the issue of the need for dedicated welfare support for people who need more intense support, explaining that Revive MS Support had developed a specialist welfare officer to meet this demand. It was noted by many attendees that people with MS were using welfare advice services, with service providers apparently inundated with need for their work.

Elizabeth Quigley said that the Group has a role in helping make sure that anyone diagnosed with MS should know what to ask for and how to ask for it, and hopes that the Group's discussions and outcomes would be widely communicated.

George Adam thanked everyone for their comments and suggestions and asked for the workplan to incorporate the suggestions, either as more detail under the initial topics or as future topics to address.

The Group agreed to proceed with the initial suggested topics for the three remaining quarterly meetings in 2014 and with the activities set out in the draft workplan, with the intention to review future topics on an ongoing basis.

The MSP members asked that the Group remain outcome and action focused and were positive about the workplan's intention to keep MS on the political agenda through relevant political and legislative activity.

Note: The draft workplan was agreed, and amendments made to incorporate the above suggestions.

4 AOCB

Following on from comments earlier in the meeting it was agreed to ensure that minutes were shared and for members to communicate final minutes within their organisations and networks as appropriate.

To manage information flow it was also agreed for the MS Society, as Secretariat, to act as a liaison for Group-wide communications. If members have any information, updates or invitations to events that they wish to share with the full Group in between meetings, the MS Society Secretariat will be happy to coordinate these on behalf of members.

The CPG on MS has members from all across Scotland and aims to be as inclusive as possible. Subject to the availability of facilities, it will aim to use video-conferencing at future meetings and to invite further afield members to join this way.

5 Date of next meeting

The next meeting will take place on Wednesday 23rd April at 6 pm and will focus on the topic of access to treatments.