

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

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<b>Date</b>	Wednesday 23 April 2014
<b>Time</b>	18:00 – 19:30
<b>Venue</b>	Committee Room 6, Scottish Parliament

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**Agenda**

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Introduction and welcome from George Adam MSP, Convener

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Minutes of the last meeting

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Improving access to MS medicines; Treat Me Right Campaign  
(Sarah Richard, MS Society)

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Discussion on access to MS medicines

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MS Week roundup

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AOCB and date of next meeting

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## Attendees

### MSP Members:

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

### Other attendees:

Duane Patterson	MS Specialist Social Worker, Dundee Social Work Department
Merv Graham	Personal interest in MS
Dr Belinda Weller	Consultant Neurologist, NHS Lothian
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
Gareth Marr	Personal interest in MS
Jacqui Downs	MS Managed Clinical Network Manager, NHS Ayrshire
Martine Douglas	Neurology Business Manager, Biogen Idec - ABPI rep
Karen Swan	Market Access and Government Affairs, Genzyme – EMIG rep
Elizabeth Quigley	Personal interest in MS
Fiona Burns	Personal interest in MS
Stacey Adam	Personal interest in MS
Mairi O'Keefe	Chief Executive, Leuchie House
Kathryn Fergusson	Head of Medicines Policy, Scottish Government
Graeme Allison	Personal interest in MS
Jonathan Randell	Biogen Idec
James Clayton	Biogen Idec
Kate Morgan	Policy Officer, Myeloma UK

### Apologies:

Nanette Milne MSP	
Bob Doris MSP	
Anne Stewart	MS Specialist Nurse, NHS Highland
Gareth Marr	Personal interest in MS
Andrew Johnston	Health Board Vice Chair, Dumfries and Galloway NHS
Dr Stewart Donald	Consultant in Rehab Medicine, NHS Lothian
Maira Flett	MS Specialist Nurse, NHS Orkney
Carly Gillespie	MS Specialist Nurse, NHS Greater Glasgow and Clyde
Iain Morrison	Chief Executive, MS Revive Support
Cat Johnson	Personal interest in MS
Jenny Preston	Consultant Occupational Therapist, NHS Ayrshire and Arran
Marion Butchart	Government Affairs Manager Scotland, Novartis - ABPI rep
Judith McSween	Speech and Language Therapist, and personal interest in MS

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## **1 Introduction and welcome from George Adam MSP, Convener**

Mr Adam welcomed members to the second meeting of the CPG on MS and noted that the meeting coincided with MS Week which was taking place the following week (28 April – 2 May). He stated that this would be the first MS Week to take place since the Cross Party Group had been established and that it was a really positive development to have the involvement of this group in raising awareness and having a focus for action this year.

## **2 Minutes of the last meeting**

The minutes of the meeting on 23/04/14 were agreed. The minutes were proposed by Fiona Burns and seconded by Martine Douglas.

## **3 Improving access to MS medicines; Treat Me Right Campaign**

Sarah Richard, Policy, Press and Campaigns Manager at the MS Society gave a presentation that looked at the current landscape of licensed MS medicines, as well as key issues that the MS Society is aware of around access to these medicines.

Key sources of evidence referred to included:

- Kobelt et al (2009) paper which discovered that the UK ranked 25<sup>th</sup> out of 27 European countries in the use of disease-modifying medicines in MS.
- The MS Society's survey findings reported in *A Lottery of Treatment and Care: MS Services in Scotland and the UK* in 2013. This found that over 60% of people with relapsing MS in the UK (64% in Scotland) were not taking any disease-modifying medicine. The survey also found that 68% of people in Northern Ireland were taking one of these medicines: more than twice the rate in Scotland.
- The same report found that only 2% of people were taking either Fampyra or Sativex which are licensed symptom management treatments designed to aid with mobility and managing severe spasticity respectively.
- MS Society Freedom of Information requests to Scotland's Health Boards which revealed that less than 10 people throughout Scotland had been able to access NHS funding for either Fampyra or Sativex between April 2012 and March 2013.
- MS Society research (2014) into treatment decision-making which found that 10% people with MS last spoke to a neurologist more than two years ago. It also found that when people had access to both information and specialists they were 69% likely to be on a treatment, compared to 7% of those who said they did not have good access to information and specialists.
- A series of MS Society *Voices for Change* focus groups held in six locations around Scotland between September 2013 and March 2014.

Some of the qualitative evidence from the *Voices for Change* focus groups was presented at the meeting. These focus groups explored in depth what the barriers to accessing licensed MS medicines are. It found some clear trends, including:

- Very low awareness among people with MS of the existence of medicines, and of there being choices between medicines.
- Very positive relationships with specialists, but concern about not being able to access specialists as frequently as needed.
- People going through long, stressful funding applications for Fampyra and Sativex, the licensed medicines that have not been approved by the Scottish Medicines Consortium.

Some of the reported experiences that were presented at the CPG included individuals who had started on Fampyra and who had then faced a year's struggle to get funding from the Health Board, during which time they had been forced to stop treatment through inability to pay or had their treatment withdrawn.

Following this overview, Sarah gave an introduction to the MS Society's Treat Me Right Campaign which was due to be launched the following week during MS Week.

A detailed summary of information from the presentation, including the research and the goals of the Treat Me Right Campaign is reflected in the meeting paper that was circulated to members in advance (appended here for reference).

#### **4 Discussion on access to MS medicines**

Questions and comments were invited from the Group. The following points were raised and discussed:

##### Access to non-SMC recommended medicines

Several members of the Group asked why Fampyra and Sativex had not been submitted for a review by the Scottish Medicines Consortium (SMC) as this was a major barrier to people accessing the medicines on the NHS.

Representatives from Biogen the manufacturer of Fampyra explained that making a submission to the SMC for Fampyra would be a huge challenge as they do not have the level and type of evidence required for critical appraisal. The company noted that it was currently working on getting data for the submission but that it would be another 5-10 years before it was in a position to make a SMC submission. The company added that it had halved the price of the product to make it more affordable to those purchasing it privately, and that it offers the product with a 4 week free drug scheme to let people see if it works for them.

Several members around the table commented that it was not acceptable to keep people waiting for access to an already licensed product for another 5-10 years and that access to it should not be restricted to those who have the financial means to pay.

In respect of the experiences shared by the MS Society there was concern about people starting a drug which proves beneficial for them and which they are then forced to stop because they cannot pay / the NHS is unwilling to pay. The company confirmed that people started on the treatment must be informed by their treating clinician that there is no guarantee the NHS will agree to funding it if they respond.

Sarah Richard confirmed that the MS Society was inviting both the manufacturers of Fampyra and Sativex to meet with them to discuss the issues around access to these medicines and it hoped that a solution could be found in the short and medium term. The MS Society wants to see these medicines available on the NHS to anyone who

needs them and is eligible for them, and the Individual Patient Treatment Request (IPTR) should be a last and temporary resort to NHS access.

Kathryn Fergusson from the Scottish Government commented that the Scottish Government had made a lot of positive changes to the processes around accessing medicines at both the SMC and Health Board levels. It is their view that the SMC route must be used to ensure equity of access to medicines; and that the Individual Patient Treatment Request (IPTR) route was not the way to increase access to medicines. She encouraged the manufacturers to engage with the SMC processes and noted that the Scottish Government would be willing to meet with the manufacturers to discuss concerns.

Dr Belinda Weller added that clinicians have a responsibility to IPTR applications as the only current route to access non SMC-recommended medicines; however she noted that it is disheartening when they are repeatedly turned down.

#### Access to MS specialists and information

Several members commented on the findings around access to specialists and its influence on people being more likely to be taking a medicine.

Graeme Allison explained that in his experience you do have to push to see a neurologist. Merv Graham said that people diagnosed more recently are more likely to see a neurologist, whereas those who were diagnosed slightly longer ago when there were no or very few treatments available would probably have been told there was little or nothing that could be offered. These people may well still be in the dark even though there are now treatments that could help.

With regard to the much higher uptake of disease-modifying medicines in Northern Ireland Karen Swan noted that one possible explanation is that there are more nurses per capita in Northern Ireland than in Scotland. Sarah Richard added that people with MS in Northern Ireland have reviews with a specialist every six months. By comparison, in Scotland the Clinical Standards for Neurology state that people with MS should be offered a review every 12 months and this is not consistently met according to the survey and anecdotal evidence gathered by the MS Society.

Becky Duff added that while people are extremely positive about their interactions with specialists, frequency of access to them and workforce planning appears to be the problem. She added that while not everyone will be suitable for or want to be on treatment, they need to have the appropriate information, support and access to be able to exercise choice.

Kathryn Fergusson proposed to ask colleagues who deal with the Clinical Standards about the question of access to specialists and the measurement of this standard.

Dr Weller noted that the Clinical Standards say that people with MS will see a member of the specialist medical team, which does not necessarily mean a neurologist, and that this standard in itself is not unreasonable. She added that high rates of prescribing does not always mean better or responsible prescribing, and that while Scotland has room to improve it critically needs the data infrastructure – around prevalence and prescribing - to support it.

#### Data and the MS Register

Dr Weller explained that Scotland needs better data as a fundamental basis for supporting better and appropriate access to MS medicines. Scotland currently does not have fully accurate data on the number of people living with a MS diagnosis, nor data on treatments that are prescribed or discontinuation or outcomes from treatment. This is a fundamental shortcoming.

Dr Weller is involved in the Scottish MS Register which is an incidence register established in 2010. She explained that it has so far collected more than 2,400 records but it is lacking approximately 20-30% case ascertainment and is under-resourced.

Several members felt that this resource was an asset with significant potential and the group agreed with George Adam's suggestion to raise the resourcing and development of the register as a priority action following the meeting.

#### Other discussion points

Dwayne Patterson explained that in his role as a MS Specialist Social Worker there are a wide variety of other barriers affecting people's adherence to their medication. It was asked whether there was any evidence on treatment adherence. This was noted as an action for follow up after the meeting.

#### Actions

The following actions were agreed:

1. The Convener and Vice-Convener to write to the Scottish Government to request further information on and support in relation to the MS Register and broader MS data infrastructure.
2. The MS Society to report back to the group on evidence around treatment adherence.
3. The MS Society to meet with the manufacturers of Fampyra and Sativex to explore issues and feed back to the group.
4. The Scottish Government to invite the manufacturer of Fampyra to meet to discuss access issues and the possibility of SMC review.

### **5 MS Week roundup**

Members shared the following information about planned MS week activity:

- MS Week Garden Lobby Reception. Wednesday 30 April, from 6 pm.
- MS Week Debate in the Chamber. Thursday 1 May, at 12 pm (*post meeting note: the transcript from this debate is appended*).
- Pop-up Leuchie event in Fife on 23 April; in-house symptom management talks at Leuchie House throughout MS Week; and a coffee morning at Leuchie House on Saturday 3 May.
- MS Therapy Centre film premiere showing of *When I Walk* at the Edinburgh Filmhouse on Monday 23 April.
- MS Social Worker, Dwayne Patterson is organising a drop-in clinic in Dundee
- The Ann Rowling clinic in Edinburgh is organising three days of *cake break* sales

### **6 AOCB and date of next meeting**

The next meeting will take place on **Tuesday 7th October** at **6 pm** and will focus on the topic of welfare reform and its impact on people living with MS in Scotland. Revive MS Support will lead the discussion with a presentation on its work in this area.