

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

Date	Wednesday 11 March 2015
Time	13:00 – 14:30
Venue	Committee Room 1, Scottish Parliament

Agenda

Introduction and welcome from George Adam MSP, Convener

Together to Beat MS: The MS Society Scotland Strategy 2015-19

CPG on MS – One Year Review

CPG on MS – Draft work plan for 2015

Update on MS Awareness Week

AOCB and date of next meeting

Attendees

MSP Members:

George Adam MSP (Convener)
Bob Dorris MSP
Malcolm Chisholm MSP
John Finnie MSP
Jim Hume MSP

Other attendees:

Harry Travers	Personal interest in MS
Stacey Adam	Personal interest in MS
Merv Graham	Personal interest in MS
Iain Morrison	Chief Executive, Revive MS Support
Aislinn Lunt	MS Society
Gillian Clifford	MS Society
Judith McSween	Speech and Language Therapist, and personal interest in MS
Duane Patterson	MS Specialist Social Worker, Dundee Social Work Department
Dr Belinda Weller	Consultant Neurologist, NHS Lothian
Dr Ruth Sumpter	Consultant Clinical Psychologist
Kathryn Fergusson	Head of Medicines Policy, Scottish Government
Martine Douglas	Neurology Business Manager, Biogen Idec - ABPI rep
Marion Butchart	Government Affairs Manager Scotland, Novartis - ABPI rep
Nigel Graham	Merek Group

Apologies:

Lewis MacDonald MSP (Vice Convener)	
Nanette Milne MSP	
Gareth Marr	Personal interest in MS
Cat Johnson	Personal interest in MS
Elizabeth Quigley	Personal interest in MS
Fiona Burns	Personal interest in MS
Graeme Allison	Personal interest in MS
Julie Craik	Personal interest in MS
Carole Macartney	Chair, MS Therapy Centre Lothian
Mairi O'Keefe	Chief Executive, Leuchie House
Anne Stewart	MS Specialist Nurse, NHS Highland
Andrew Johnston	Health Board Vice Chair, Dumfries and Galloway NHS
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
Jenny Preston	Consultant Occupational Therapist, NHS Ayrshire and Arran
Jacqui Downs	MS Managed Clinical Network Manager, NHS Ayrshire
Kate Morgan	Policy Officer, Myeloma UK
Natalie Frankish	Genetic Alliance
Simon Coates-Walker	Ethical Medicines Industry Group

2 Introduction and welcome,

The Convener welcomed attendees and accepted apologies.

Dr Ruth Sumpter, Consultant Clinical Psychologist, Dept. of Neuropsychology, Institute of Neuroscience, Southern General Hospital was welcomed as a new member. Dr Sumpter is replacing Dr Steven Meldrum on the Group. The Convener thanked Dr Meldrum for his involvement and contribution.

3 Together to Beat MS: The MS Society Strategy 2015-19

The MS CPG welcomed guest speaker Aislinn Lunt, Head of Policy and Communications, MS Society Scotland. Aislinn outlined that during 2014 the Society worked alongside people affected by MS, volunteers and staff to develop a new strategy. The strategy has now been approved by the charity's Board of Trustees, and endorsed by members, and will guide the MS Society's work from 2015 to 2019.

The MS Society's vision and mission haven't changed. They will continue to be an organisation that works towards the cure we all want to see, whilst also supporting everyone affected by MS in the here and now.

The strategy is underpinned by seven organisational goals:

- Effective treatments
- Responsive care and support
- Preventing MS
- Quality information
- A strong community, independent lives
- Supporting families and carers
- Greater certainty about the future

Discussion ensued around the strategy with clarification being sought around how MS can be prevented when the cause is not yet known and whether the plan was UK wide or Scotland specific. Aislinn outlined that the MS Society is UK-wide organisation working under one strategy, with a strong Scottish identity – rooted in local communities through their branches and supported by a Scotland staff team who are fully committed and best placed to understand the different landscape in Scotland.

Aislinn also gave a short update on the MS Society's General Election campaign. Too many people affected by MS in the UK have to fight for the treatments, services, care and support they need. The MS Society's campaign aims to change that. They are asking their members and supporters to give MS a voice in the next Westminster Government.

The Convenor noted that hustings events will take place across the country and stressed that members could use this opportunity to highlight that MS is relevant to the current general election discussions.

The MS Society's General Election campaign asks its supporters to

- get loud on the doorstep and during hustings
- use the MS Society campaign tools
- get in touch with their local candidates online
- sign up to the MS Society email updates.

4 CPG on MS – One Year Review

The Convenor outlined that the achievements of the CPG for MS were a result of the range of partners involved. The importance of reflecting this in the one-year review was noted. The members noted the one-year review.

5 CPG on MS – Draft workplan for 2015

Aislinn Lunt gave an overview of the draft workplan for 2015, attached, for members' consideration and input. Discussion ensued around the Scottish Government's recent announcement on additional funding for specialist nurses and the potential impact of the integration of health and social care on people with MS. It was agreed that these two issues would be brought together as one topic in the workplan and would continue to be a central piece of work for the CPG.

It was noted that a debate on integration of health and social care will place next week.

The workplan was agreed with the amendment that specialist nursing and integration were linked more clearly.

6 Update on MS Awareness Week

Gillian Clifford, MS Society, provided an update on the MS Society's plans for MS Awareness Week.

The MS Society will be at the Scottish Parliament throughout the week with a week-long exhibition, on the theme of 'My MS, My Life', which will focus directly on people with MS, their families and carers and on their experiences of living with MS. It will aim to highlight a range of issues, from treatment, care and support, working with MS, choice and independence.

The MS Society will also host a Parliamentary Reception from 6 to 8pm on Wednesday 29 April. Paralympics GB swimmer Stephanie Millward has been confirmed as the guest speaker. Stephanie is a previous winner of MS Inspiration of the Year. After being diagnosed with MS aged 17, Stephanie went on to win 5 medals at the London 2012 Paralympics, including 4 silvers. Other speakers at the event will be:

- Jamie Hepburn, Minister for Sport, Health Improvement and Mental Health
- Stacey Adam, who is living with MS
- Mary Douglas, Chair of the MS Society Scotland Council.

George Adam, MSP, advised that his team are working to secure a debate in the Scottish Parliament during the week.

7 AOCB

Concern was raised around the lack of trials investigating progressive MS, and it was noted that that MS Smart study specifically looks at Progressive MS.

Harry Travers, MS Society Ayrshire & Arran Branch Chairman, raised a question around the unacceptable delay in waiting times for out-patient neurology consultations in his local area. The local Health Board is currently not meeting the Scottish Government Standard of 12 week maximum waiting time.

Action: George Adam MSP agreed to address this issue of behalf of the committee with the Cabinet Secretary for Health.

Actions

The following actions were agreed:

1. The MS Society, as secretariat for the CGP, to update the workplan.
2. The Convener and Vice-Convener to write to the Cabinet Secretary for Health to request further information delay in waiting times for out-patient neurology consultations in Ayrshire & Arran.

8 Date of next meeting

The next meeting will take place on **Wednesday 22 April 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.