

CROSS-PARTY GROUP REGISTRATION FORM

NAME OF CROSS-PARTY GROUP

Cross-Party Group on Multiple Sclerosis (MS)

PURPOSE OF THE GROUP AND PROPOSED DISCUSSION TOPICS

1. Please provide a brief explanation of the purpose of the Group and why the purpose is in the public interest.
2. Please also provide details of any overlaps with the purpose of existing Cross-Party Groups and an explanation of why, regardless of any such overlap, the Group should be established.
3. Please also provide an indication of the topics which the Group anticipates discussing in the forthcoming 12 months.

1. Multiple Sclerosis (MS) affects more than 10,500 people in Scotland; this is one of the highest incidences of the condition in the world. MS is a complex, incurable and debilitating condition. However, with the right care and support people can live independent, high quality lives.

MS is a life long condition that affects people from an early age. Most people are diagnosed during their 20s and 30s and then face a lifetime with this complex condition. People affected by MS - both those diagnosed with MS and thousands of unpaid carers - often face significant health, social care and financial challenges due to the condition itself and the availability of the right services and support.

The main purpose of the Group is to address the needs of people with MS in Scotland by bringing together those with an interest in the health and wellbeing of persons living with this condition.

The Group will promote discussion of MS issues, raise awareness, share good practice locally and nationally, and increase understanding of MS across a range of services and within the Parliament.

The purpose of the Group links closely to national framework priorities, including *living longer healthier lives* and *tackling inequalities*. In particular the aims of the Group support the national framework indicators to improve the quality of healthcare experience; reduce emergency admissions to hospital; and improve support for people with care needs.

2. There is strong support from MSPs and charities for a Cross Party Group focussed specifically on the condition in order to address the issues in a meaningful way.

MS touches every community in Scotland with a prevalence of 1 in 500 people.

There are existing Cross Party Groups that deal with single issues also affecting people with MS: notably the CPG on Carers and the CPG on Disability. However these Groups do not deal with the breadth of issues that need to be addressed to improve the lives of those living with MS.

A specific MS focus is required on access to MS healthcare and neurology services and the further development, implementation and monitoring of condition-specific standards. This will form a major part of the Group's work and can only be dealt with through a CPG on MS.

The CPG on MS envisages collaborating with other Cross Party Groups such as the CPG on Carers and the CPG on Disability on issues of shared interest.

3. The CPG will influence meaningful improvements in a number of key policy areas for those affected by it in Scotland.

It anticipates establishing a clear agenda and discussing the following topics in the next 12 months:

- Implications from MS Society research into the needs and experiences of people with MS in Scotland and the UK (*A lottery of treatment and care 2013*)
- MS healthcare standards in Scotland – the Neurological Standards framework and Health Board compliance; taking the standards further in the context of health and social care integration
- Improving access to MS treatments and clinical research in Scotland
- Challenges in social care provision for people with MS

Expert speakers and non-members with a specialist interest will be invited to contribute to appropriate meetings.

MSP MEMBERS OF THE GROUP

Please provide names of all MSP members of the Group. Note that only names need to be provided, no party designation or other information is required.

George Adam MSP

Lewis MacDonald MSP

John Finnie MSP

Neil Findlay MSP

Jamie Hepburn MSP

Nanette Milne MSP

Jim Hume MSP

Bob Doris MSP

Stuart Stevenson MSP

NON-MSP MEMBERS OF THE GROUP

For organisational members please provide only the name of the organisation, it is not necessary to provide the name(s) of individuals who may represent the organisation at meetings of the Group.

Individuals

Cat Johnson, Person with MS, MS Society Scotland Council member

Gareth Marr, Person with MS, MS Society Scotland Council member

Merv Graham, Family carer of someone with MS

Jenny Preston, Consultant Occupational Therapist, NHS Ayrshire and Arran

Dr Lorna Paul, MS Physiotherapist and Researcher, NHS Greater Glasgow & Clyde

Duane Patterson, MS Specialist Social Worker, NHS Dundee

Anne Stewart, MS Specialist Nurse, NHS Highlands

Andrew Johnson, Health Board Vice Chair, NHS Dumfries and Galloway

Dr Belinda Weller, Consultant Neurologist, NHS Lothian

Dr Stuart Donald, Consultant in Rehab Medicine, NHS Lothian

Dr Judith McSween, Speech and Language Therapist, Person with MS

Organisations

MS Society

Revive MS Support

ABPI Scottish Mental Health and Neurological Disease Industry Group

GROUP OFFICE BEARERS

Please provide names for all office bearers. The minimum requirement is that two of the office bearers are MSPs and one of these is Convener – beyond this it is a matter for the Group to decide upon the office bearers it wishes to have. It is permissible to have more than one individual elected to each office, for example,

co-conveners or multiple deputy conveners.	
Convener	George Adam MSP
Deputy Convener	Lewis MacDonald MSP
Secretary	MS Society
Treasurer	N/A
FINANCIAL BENEFITS OR OTHER BENEFITS	
Please provide details of any financial or material benefit(s) the Group anticipates receiving from a single source in a calendar year which has a value, either singly or cumulatively, of more than £500. This includes donations, gifts, hospitality or visits and material assistance such as secretariat support.	
Secretariat support from the MS Society is estimated at approximately £1,000 – £1,500 for the calendar year. This estimate includes a provisional value of staff time, printing of information packs, catering costs, phone calls and speaker travel.	
SUBSCRIPTION CHARGED BY THE GROUP	
Please provide details of the amount to be charged and the purpose for which the subscription is intended to be used.	
None	
CONVENER CONTACT DETAILS	
Name	George Adam MSP
Parliamentary address	The Scottish Parliament Edinburgh EH99 1SP
Telephone number	0131 348 5869

STATEMENT ON COMPLIANCE WITH THE CODE OF CONDUCT
I declare that the Cross-Party Group on Multiple Sclerosis is constituted and will

comply with the terms of Section 6 of the Code of Conduct for Members of the Scottish Parliament.

Signed	George Adam
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Date	2/10/13
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