

CROSS PARTY GROUP ON MULTIPLE SCLEROSIS (MS)

Notes of Meeting on Tuesday 4 June 2019,
held at Scottish Parliament

In Attendance:

George Adam, MSP
Heather Armstrong, MS Society
Marion Butchart, Novartis
Claire Cairns, Coalition of Carers and Scotland
Margaret Campbell, MS Revive
Jacqui Downs, NHS Ayrshire & Arran
Rebecca Duff, MS society
Hannah Evans, Merck
John Finnie MSP
Yasmin Fraser, Biogen
Rebecca Hogarth, Novartis
Keith Robson, MS Society Scotland
Greg Stevenson, Roche

Apologies:

Stacey Adam
Claire Adamson MSP
Mark Bevan, Leuchie House
Claire Bryan, MS Society Scotland
Mhairi Coutts, NHS Ayrshire & Arran
Mary Douglas, Council Member MS Society
Angela Feharty, Revive MS Support
Neil Findlay MSP
Elinor Jayne, Sue Ryder
Cat Johnson
Lynda Kearney, Lead Specialist MS Nurse
Liam McArthur MSP
Angela McCormack
Sarah Mather
Iain Morrison, Revive MS Support
Paru Naik, MS Trust
Elizabeth Quigley
Jenny Preston, NHS Ayrshire & Arran
Angela Simonds, Celgene
Morna Simpkins, MS Society Scotland
Ruth Sumpter
Karine Whitton

1. Welcome and Introductions

George Adam MSP welcomed attendees to the meeting.

2. Matters Arising from previous meeting

Action:

- Group agreed to write to HIS to enquire about timelines and seek assurances regarding condition specific standards

George Adam and Keith Robson apologised as this had fallen through the cracks and not been actioned. In the meantime the National Standards had been published. A letter will be sent out to HIS regarding the need for condition specific standards.

Action:

- Group agreed to defer the item on Patient Pathways until the next meeting

It is agenda item 4

3. Update on Treatments and Research

The [Scottish Health Technologies Group](#) (SHTG) is the national health technology assessment (HTA) agency. It provides evidence support and advice to NHS Scotland on the use of new and existing health technologies which are not medicines and which are likely to have significant implications for people's care.

The MS Society is in discussion with the HSCT Scotland network to submit a joint response to the SHTG when Autologous haematopoietic stem cell transplantation (HSCT) is considered by the Group in September. If approved then it should make it easier for HSCT to be available via the Health Boards in Scotland. The consultation closes on 24 June. The MS Society wants to see the same eligibility criteria and pathway as approved by NICE in England.

A discussion took place about clinical trials and the repurposing of medicines.

Actions:

- Invite Professor Siddharthan Chandran and Dr Govindish Chavada to a future meeting to discuss clinical trials
- KR to ask for copy of Professor Chandran's presentation to ABDN on HSCT pathways to circulate to the Group

4. Patient Pathways: Issues with access to treatments

Rebecca Duff informed the meeting that MS Society is looking to scope out 'what good would look like' for access to treatments, as part of a wider UK wide project exploring unwarranted variation in MS services. Events are being run for people living with MS as part of that exercise. Neurology has never been higher on the agenda in the Scottish Parliament and the opportunity exists to influence improvements.

The Group was in agreement that there should be a simple pathway for patients, which does not necessarily focus on GPs. MS Nurses, physiotherapists, pharmacists could all make a valuable contribution to the care of patients within a clinical setting. Greg Stevenson referenced a report from 2005 regarding Care in Local Settings which has never been fully implemented.

The importance of a public health campaign which reflects

A discussion also occurred as to how the Neurological Standards and the Neurological Action Plan can be used to improve patient pathways and hold Health Boards and Integrated Joint Authorities to account. There was a belief that the current MS specific Standards which are still live are not being met. There were lots of examples given as to patients' waiting times for referrals. It was suggested that the time taken to wait for a MRI would be a good indicator and place MS patients on a similar plateau to cancer patients and their waiting times. The Scottish MS Register is measuring waiting times and Healthcare Improvement Scotland should be holding Health Boards to account.

Action:

- KR to email the link to the My MS My Needs Survey to CPG members

5. Future Work of the CPG

Action:

- Invite Jean Freeman MSP, Cabinet Secretary for Health and Sport, along with Gerald Gahagan, National Implementation Lead (Neurological Conditions National Action Plan) to December meeting.
- KR to provide GA with a list of potential CPGs we may wish to work collaboratively with during the next session

6. A.O.C.B.

Provisional Dates of 2019/20 meetings (TBC)

- 10 September 2019
- 10 December 2019
- 10 March 2020
- 9 June 2020