

Cross Party Group on Multiple Sclerosis (MS)

Minutes

**Tuesday 7th February 2017
6 pm – 8 pm
Scottish Parliament – TG20.21**

Attendees: Carole Macartney, Elinor Jayne, Mairi O'Keefe, Rebecca Hogarth, Marion Buchart, Yasmin Fraser, Mervyn Graham, Greg Stevenson, Becky Duff, Niall Sommerville, Geraldine Mynors, Stacey Adam, Morna Simpkins

MSP Attendees: George Adam MSP, John Finnie MSP, Donald Camron MSP

Apologies: Angela Feherty, Iain Morrison, Elizabeth Quigley, Belinda Weller, Harry Travers, Alastair Ross, Simon-Coates Walker, Margaret Burgess, Ruther Sumpter, Fiona Burns

1. Welcome and introductions

George Adam MSP welcomed members to the CPG and noted apologies. Minutes were proposed by Merv Graham and seconded by Carole McCartney.

2. Update on actions from previous meetings

Niall Sommerville talked through the letter the CPG sent to the Scottish Government regarding employment and MS. The Scottish Government have now responded highlighting actions they are taking which will address some of the issues in the report. They also commented on the upcoming employability changes due to devolution and the opportunities these will afford. This response was welcome and will help with future working.

At the previous meeting it was discussed that letters should be sent from the CPG to NHS Lanarkshire and the Scottish Government regarding the continuing MS Nurse resource issue. It was agreed this would be done following the outcome of discussions between the MS Trust and NHS Lanarkshire. These discussions have been ongoing and as such only recently reached a conclusion so the opportunity to write has only now become available. The letters will now be sent and circulated amongst members.

3. MS Trust – Forward View Project

Geraldine Mynors from the MS Trust presented findings from the MS Forward View project. This was a one year project, run in 2016, which brought together stakeholders from across the UK MS sector: clinicians and their professional organisations, the NHS, patient organisations, people with MS and industry, to build a consensus on the actions needed to improve MS care in the context of increasing

DMD treatment. Geraldine reported that there are now 26 whole time equivalent MS specialist nurses in Scotland (up by 3.4 WTE since 2014), but there remain areas of Scotland where caseloads are far in excess of sustainable levels - particularly Lanarkshire and Lothian. She explained the MS Trust's Specialist Nurse funding programme which has recently been launched. She highlighted that the workload around DMD prescribing continues to increase and that it will be important for teams to take measures to improve efficiency, for example by employing DMD coordinator posts, if this is not to overwhelm services. She highlighted recommendations for people with advanced MS, including that each MS service should have a lead for advanced MS. The reports of the work are available to download at www.mstrust.org.uk/forwardview

4. Sue Ryder – Rewrite the Future

Elinor Jayne from Sue Ryder presented the key findings from the research behind the Sue Ryder Rewrite the Future campaign. These demonstrated the need to change the way care is provided for people with neurological conditions to ensure that all services are designed around people who use them. Members of the CPG contributed to ideas for the next stage of the campaign and Elinor committed to coming back to the CPG with new findings. George Adam MSP as Convenor indicated the CPG would like to use these to make the case for better integration of health and care services for people with MS and other neurological conditions.

5. MS Awareness Week

Niall Sommerville from the MS Society talked through their plans for MS Awareness Week. The focus will be on MS Nurses, highlighting the important role they play in helping people manage their MS as well as possible. Plans for the week include an exhibition in Parliament, an event in Parliament on Wed 26 April, members debate, social media activity, and more. CPG members agreed to share any plans for MS Week.

6. Neurological Alliance

Rebecca Duff, MS Society, gave an update of the working and plans of the Neurological Alliance. It was suggested by CPG members that they could feed into the work of the Neurological Alliance.

7. AOCB

Carole McCartney noted it would be interesting to look at other CPGs and see whether there are any we could do joint work with. Niall Sommerville agreed to do some mapping of other relevant CPGs.

It was noted that the Clinical Standards for Neurological Health Services that contains the key measures for MS are to be renewed. This was deemed a very positive move and one that could drive forward removal of geographic variations in

clinical services (such as we see at the moment with Lothian and Lanarkshire). The timelines for development were not available. It was also discussed that there is an ongoing debate in Scottish Government as to whether Clinical Standards should be continued. This could cause the demise of the Clinical Standards. Consensus was that this is would be an undesirable situation. It was agreed in the meeting that a "pre-emptive" letter from the CPG should be sent to HIS and specifically those renewing the Standards that we felt Standards renewal was needed.

It was noted that the Scottish Government had recently met its pledge on funding Phd places on MS research. This was welcomed by members.