

Cross Party Group on Multiple Sclerosis (MS)

Minutes

Tuesday 18 April 2017

6 pm – 8 pm

Scottish Parliament – TG20.21

Attendees: Stacey Adam, Mary Douglas, Lorraine Hunter, Damian Crombie, Yasmin Fraser, Janice Thomson, Nigel Graham, Keith Dryburgh, Iain Morrison, Greg Stevenson, Becky Duff, Morna Simpkins, Niall Sommerville

MSP Attendees: Clair Adamson MSP, George Adam MSP

Apologies: Jacquie Downs, Judith MacSween, Carole Macartney, Fiona Burns, Donald Cameron MSP, Margaret Burgess, Gail Ross MSP, Mairi O'Keefe, Ruth Sumpter, Elizabeth Quigley, Merv Graham, Alastair Ross, John Finnie MSP, Geraldine Mynors, Jenny Preston

1. Welcome and introductions

George Adam MSP welcomed members to the CPG and noted apologies. Greg Stevenson noted that a discussion relating to Clinical Standards for Neurological Health Services had been missed from the AOCB section of the previous minutes. Niall Sommerville agreed to update the minutes with a note on the discussion.

2. Update on actions from previous meetings + update on NHS Lanarkshire

Following the last meeting the CPG sent letters to the Scottish Government and NHS Lanarkshire regarding the ongoing MS nurse situation in Lanarkshire. The responses were discussed by the CPG. It was noted that the situation in Lanarkshire is reaching crisis point as the current nurse is to leave their post on Fri 28 April.

Iain Morrison raised a number of concerns with the responses and that they did not provide an accurate picture. George Adam noted that the NHS Lanarkshire letter states they are creating a plan for MS services. CPG agreed they should write to NHS Lanarkshire asking to see their plan. Niall Sommerville, Iain Morrison and George Adam MSP to draft a response to NHS Lanarkshire covering this issue and inaccuracies highlighted in the letter. The CPG also agreed to write to the Cabinet Secretary for Health and Sport to ask about the Scottish Government's long term plan for MS specialist nursing. It was suggested this should include a request for a meeting.

Janice Thomson asked whether there has been any work with NHS Lothian to try and get additional MS nurses. Becky Duff responded saying that MS Trust has been working with NHS Lothian to build a business case for additional MS nurse provision.

Iain Morrison highlighted the issue of morale in the NHS - believes the Scottish Government should be looking at why clinicians such as Mairi Coutts are willing to leave the NHS to work in the third sector.

Damian Crombie noted his concern about any possible move away from specialist nursing, not just in terms of MS nurses but considering other specialties too. The CPG agreed that due to the integration of health and social care it would be useful to speak to new councillors about the issues.

3. MS Week Plans

Niall Sommerville talked through the MS Society's plan for MS Week. It was noted that as with previous discussions the key theme would be around MS nurses, demonstrating the important role they play and gathering political support for the role of MS nurses. Activities for the week include: Exhibition in Parliament, Parliamentary reception, members debate on MS nurse, blogs, videos, press activity, community activity. CPG members have all been invited to the Parliamentary reception. George Adam will lead the debate in Parliament on Wednesday.

Lorraine Hunter said that Leuchie House will focus on the importance of respite care throughout MS Week. Iain Morrison added that Revive MS will have the official opening of their new premises on the Tuesday of MS Week and this will be attended by the Minister for Public Health and Sport.

All members were encouraged to share each other's content throughout the week.

4. Daclizumab and Ocrelizumab – Updates

Becky Duff talked through recent developments in MS medicines. She noted that Daclizumab had recently been approved for use by the SMC making it the 12th DMT licenced for use by people with relapsing remitting MS on the NHS in Scotland. It was noted that the strong patient group submission was welcomed during the evidence session of the SMC and gives confidence that the voices of patients is being taken into account during the SMC process.

Ocrelizumab has recently been approved by the FDA for use by people with relapsing remitting and primary progressive MS. This is the first drug approved in the world for primary progressive MS. This is a potentially exciting development and it will now go forward for approval in Europe before potentially being considered by the SMC.

5. Social Security – Scottish Govt response to consultation – discussion and next steps

George Adam MSP introduced the topic of Social Security and talked through the recent response to the consultation published by the Scottish Govt. There were many areas of encouragement within this of an improved system of social security,

however, it's important we continue to push for a system that meets the needs of people with MS.

Clare Adamson advised that her office would be running a session encouraging people to sign up to experience panels.

Keith Dryburgh noted that alongside the route of experience panels we need to keep advising the Government with our collective knowledge and look for any opportunities that may arise. Iain Morrison added that Govt needs to continue to visit people and involve potential service users before creating policy.

It was agreed that the next CPG session would focus on Social Security and that we will invite Jeanne Freeman MSP, Minister for Social Security, to attend. Keith Dryburgh suggested that we invite Jim McCormack, Chair of the Govts Disability & Carers Benefits Expert Advisory Panel. Finally, there was a suggestion we involve other CPGs in this meeting.

6. MS and Employment / Continence

Damian Crombie talked about the impact that continence issues can have on employment for people with MS. He was keen to raise the topic and increase awareness, in particular looking at how people can be better supported to remain in employment. Iain Morrison noted that at present there are long waiting times to access continence services on the NHS. Janice Thomson agreed that this was an issue and that we also need to help people at a younger age so that they can remain in or access employment.

7. AOCB

Iain Morrison talked through the ARMMS project that Revive MS are launching and noted it will be up and running within the next few months. He talked through the support the project will offer, such as telehealth. HIS are involved in funding this project, the first pilot of its kind, so it is very much a collaborative project.

Meeting closed 19:50