

## **Cross Party Group on Multiple Sclerosis (MS)**

### **Minutes**

**Tuesday 20<sup>th</sup> September 2016**

**6 pm – 8 pm**

**Scottish Parliament – TG20.21**

#### **Attendees:**

##### **MSP Members:**

George Adam MSP (Convenor)

Lewis Macdonald MSP

Liam McArthur MSP

Donald Cameron MSP

John Finnie MSP

##### **Other attendees:**

Niall Sommerville, MS Society

Rebecca Duff, MS Society

Stacey Adam, Personal interest in MS

Merv Graham, Personal interest in MS

Jaqui Downs, NHS Ayrshire and Arran

Dr Belinda Weller, NHS Lothian

Marion Butchart, Novartis

Angela Faherty, Revive MS

Angela McCormick, MS Society

Dean Reilly, Lothians MS Therapy Centre

Elinor Jayne, Sue Ryder

Elizabeth Quigley, Personal interest in MS

Fiona Burns, Personal interest in MS

Geraldine Mynors, MS Trust

Margaret Burgess, MSS Ayrshire and Arran

Ruth Sumpter, NHS GGC

Sam Graham, Biogen

Stuart Carrol, Biogen

#### **Apologies:**

Neil Findlay MSP

Claire Cairns, Coalition of Carers in Scotland

Cat Johnson, Personal interest in MS

Carolyn Roulstone, Leuchie House

Nancy Campbell, Lothians MS Therapy Centre

## Minutes

### 1. Welcome and Introductions

George Adam MSP welcomed members to the first CPG on MS meeting of the new Parliamentary session and noted apologies.

### 2. Election of Office Bearers

As this was the first CPG of the Parliamentary term it doubled as the AGM. The following were elected as office bearers:

**Convenor – George Adam MSP**; Proposed by John Finnie MSP and Seconded by Lewis Macdonald MSP

**Vice Convenor – Neil Findlay MS**; Proposed by Lewis Macdonald MSP and Seconded by George Adam MSP

**Secretariat – MS Society Scotland**

### 3. My MS My Needs report

Rebecca Duff from the MS Society talked through their recent report into access to treatments, care, and support, for people with MS in Scotland. The report 'MS treatment in Scotland: Is access still a lottery?'. The report follows a survey of 939 people living with MS in Scotland and is the second report of its kind; the first report was released in 2013. Key findings included:

- 57% of those who could potentially benefit from taking a disease modifying therapy (DMT) are doing so (an increase from 36% in 2013).
- 72% of those who had seen an MS nurse in the last 12 months were taking a DMT, compared to 10% who had not seen an MS nurse within a 12 month period.
- 84% of respondents had not been offered a care plan by their health professionals.
- 85% of respondents had their need for access to a neurologist met (an increase from 75% in 2013).

The report also made a number of recommendations, including:

- Everyone living with MS should have an annual review with their MS specialist to discuss their treatment options, regardless of how long they have been diagnosed, as recommended by the 2009 Clinical Standards for Neurological Services.
- People with MS should be offered a comprehensive review with an MS specialist at least once a year that draws on expertise across a multidisciplinary team.
- All people with MS should be offered a care plan, which should be regularly reviewed.
- All licensed treatments for MS should be made available on the NHS in Scotland, through local health board formularies.

Rebecca Duff noted that these findings are very much a starting point and that the MS Society would be undertaking further work to understand them better and

what they mean for MS care and support in Scotland. There was a brief discussion about whether access to specialists is done in a hospital setting or community setting and what is most appropriate.

#### **4. Scottish MS Register National Report 2016**

Dr Belinda Weller talked through the findings of the MS Register National Report 2016 and gave some background to the Scottish MS register. Noted the key findings including:

- In 2015, 530 new patients were added to the MS register as having a confirmed diagnosis of MS. Total number newly diagnosed and on register over the six year period now 2,731.
- 63% of newly diagnosed patients had contact with a MS nurse specialist within 10 days.
- Once a referral was received by the MS nurse specialist, contact within 10 days was achieved for 89% of the patients which is an improvement of 4% from 2014.
- The mean national incidence rate in last six years is 8.5 per 100,000.

Dr Weller noted that there will be more research and data to come funded by the Scottish Government.

#### **5. MS Trust 'Forward View'**

Geraldine Mynors, GEMSS Programme Manager at the MS Trust, presented the first findings of the MS Forward View project. This is a one year UK-wide project led by the MS Trust but involving many other stakeholders which is aiming to define the priorities for improving MS care across the sector. As part of the project, the MS Trust had created an interactive map of all MS teams across the UK which is available at [www.mstrust.org.uk/msfv-map](http://www.mstrust.org.uk/msfv-map). Findings of the project include:

- MS teams are becoming overwhelmed with the burden of prescribing and monitoring disease modifying drugs. Whilst increased treatment rates are very welcome, this means that people with MS not on DMDs are less likely to see an MS specialist nurse or neurologist.
- The number of MS specialist nurses has increased from 22 to 26 across Scotland since 2014.
- Nevertheless, there remain many parts of Scotland where caseloads for MS nurses are far in excess of the sustainable level (recommended as 358 people with MS per full time nurse). NHS Lanarkshire and NHS Lothian's nurses have caseloads well in excess of 900 people with MS per nurse.
- Nurses are also struggling because of a lack of admin support, meaning that they have to do many non-clinical tasks.

Geraldine explained that the MS Trust had recently launched a nurse funding programme to pump prime new MS nurse posts in the NHS, and that NHS Lanarkshire had been shortlisted for the first round of the programme. The full

reports of the MS Forward View project will be published in early November. George Adam asked whether the funding of MS nurses via fundraising was letting the NHS and Scottish Govt “off the hook”? Geraldine noted that this was a slight concern but believes that in areas of need we need to use a different approach to get the issue noticed. Becky Duff added that if done properly this could create a strong evidence base and robust ask.

## **6. Social Security Bill**

Niall Sommerville introduced the topic of the Social Security consultation currently being run by the Scottish Government and talked through the engagement the MS Society had undertaken with the MS community. It was noted that the consultation closes on 28<sup>th</sup> Oct and that a strong voice from the MS community would be powerful. Niall will circulate the MS Society response once completed.

## **7. Fampyra**

Rebecca Duff noted that the SMC is currently considering Fampyra and whether it should be available on the NHS in Scotland. It was noted that if successful Scotland would be the first place in the UK to make Fampyra widely available. Stuart Carroll talked about the submission, evidence used and how we have got to the position thus far. A decision on Fampyra is expected in early November.

## **8. A.O.C.B**

The next CPG meeting is scheduled for Tues 29 November and will focus on employability and employment issues for people with MS.

Meeting closed 19:30