

## **CROSS PARTY GROUP ON MULTIPLE SCLEROSIS (MS)**

Notes of Meeting on Wednesday 4 December 2018,  
held at Scottish Parliament

### **In Attendance:**

George Adam, MSP (in part)  
Liam McArthur MSP (in part)  
Stacey Adam  
Claire Bryan, MS Society Scotland  
Jacqui Downs, NHS Ayrshire & Arran  
Angela Feharty, Revive  
Rebecca Hogarth,  
Angela McCormack  
Stuart Milne, MS Society Scotland  
Iain Morrison, Revive  
Jenny Preston, NHS Ayrshire & Arran  
Keith Robson, MS Society Scotland  
Morna Simpkins, MS Society Scotland  
Niall Sommerville, MS Society Scotland  
Greg Stevenson, Roche

### **Apologies:**

Mark Bevan, Leuchie House  
Marion Butchart, Novartis  
Mhairi Coutts, NHS Ayrshire & Arran  
Mary Douglas, Council Member MS Society  
Cat Johnson  
Elizabeth Quigley  
Steven Tait, Council Member MS Society

### **MEETING**

Liam McArthur MSP in the absence of the Convenor George Adam MSP welcomed attendees saying he hoped there would following a seamless handover before he had to leave the meeting around 6.45pm. At that moment George Adam MSP arrived and took the chair.

There were no amendments to the minutes of the meeting of the CPG and no matters arising and the minutes were subsequently approved.

## **Update on Treatments and Research**

Niall Sommerville updated the CPG on the September meeting of the Scottish Medicines Consortium (SMC) where Fampyra was considered but not approved. A meeting has been set up with Biogen to discuss how this can be moved forward to a successful outcome.

Niall informed the CPG that private notification of the SMC's decision on Ocrelizumab (Ocrevus) was due on Wednesday 5 December. It would then be embargoed until Monday 10 December. It had originally been rejected in the summer and with a quick resubmission.

## **Neurological Standards Consultation and Neurological Action Plan Consultation**

The next two items were to be taken concurrently.

Keith Robson introduced Jenny Preston who had kindly agreed to talk to both the Standards and Action Plan consultations as a member of both working groups. The Standards consultation is being run by Health Improvement Scotland (HIS) and the Action Plan consultation by the Scottish Government.

This is the first part of the revision of the Standards. Disease specific standards will follow, the generic standards are to be completed first. There was a real desire by the working group to develop standards which just weren't health focussed. So they could incorporate a range of situations from diagnosis through to end of life care.

Niall Sommerville welcomed the aspirations within the Action Plan and asked about measurement of the Plan and resources required for implementation. Jenny replied by saying that HIS develop Standards but don't monitor them. There is a link to the Standards in the Action Plan.

The Scottish Government are working on the implementation of the Plan. Jenny's understanding is that finance will be attached to the Implementation Plan where needed.

Niall asked where measurement would sit in terms of accountability. Jenny said that there was a wide range of views on this within what was a wide working group. Do you improve standards by compliance or by helping everyone to have their own improvement plans? There will have to be some mechanism of accountability and be measured. Currently only two Boards meet the Standards re MS and work is ongoing in that area.

The consultation is an open process and really want to hear from people and get the feedback.

Iain Morrison said that he thought there is a major piece of the jigsaw missing between the Standards and the Action Plan. Will it be an addendum to HIS Generic Standards? Jenny isn't in a position to say how HIS will take forward the next piece of work

Niall expressed the MS Society's concerns that the generic Standards will be seen as superseding the current condition specific standards.

Iain asked whether or not we should go to HIS for reassurance? Jenny said it is likely that condition specific standards are still current and we should be reporting against them.

Iain enquired as to the future role and function of NACNC and NAG. Who will monitor them?

Greg Stevenson suggested we should reflect on Diabetes and Cancer where very strong civil servant in place to monitor and manage their respective plans.

Jenny said there will be a National Lead within the Action Plan.

Greg further suggested that it is a critical appointment, the successful candidate must have gravitas. The clinical standards must sit alongside the Plan.

Morna Simpkins said that the Action Plan wasn't written as a strategy. How much improvement are we going to see within the IJBs?

Iain believes that in fairness to NACNC neurology has been well represented and included the third sector. Does the Scottish Government have the will to realign funding away from acute health to third sector?

Greg said that even if the government hates it ring fencing works.

George offered the thought that it was back to the arguments of historic concordat versus ring fencing again

Niall thought that it was important to say that the Action Plan has really raised the profile.

Action:

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

Liam McArthur left the meeting

## **Patient Pathways**

Rachel Morrison, Specialist MS Nurse NHS Western Isles, was due to lead a discussion on patient pathways however was unable to attend tonight's meeting.

### Action:

- Group agreed to defer the item until the next meeting

## **Experiences of people with MS Pre-diagnosis**

Iain Morrison and Angela Feharty, Revive MS led this discussion.

Iain reported that increasingly over the past three to four years people were using Revive's services prior to a diagnosis. They were aware of their own condition and had not received the support they'd expected from their GPs. The impact on individuals had been ranged from losing their job, their house and giving up places at university.

Revive believed that everything starts at diagnosis. The average length of time between first time symptoms presented themselves and diagnosis is ten years.

Disability benefits and critical illness cover do not come into effect until diagnosis. Neither do occupational health departments recognise it before diagnosis.

Thousands are living with MS, undiagnosed and unsupported.

Angela said that they had got a MS Nurse to look at random selection of one hundred and twenty clients. The average length of time before diagnosis was 9.6 years.

The average age in Scotland is 41 and in England it is 31

Angela said that 99% of Revive clients diagnosed under a year had paid for it.

CIS is catch all. In America 96% of people with CIS have MS.

Niall said that the Action Plan commits to rapid access clinics for Epilepsy. Should we be looking to replicate that for MS?

A discussion followed on peoples' poor experiences of provision of MS services and their own route to diagnosis.

Greg suggested that MS has always been behind the curve in science research. There is an opportunity to have blood test for MS just like Diabetes.

George suggested that he could write to the Cabinet Secretary that there is a belief this is an issue. Would like an explanation on the long lead in time to diagnosis.

Jacqui Downs asked how CIS is treated between different Boards? They should have access to MS Nurses.

**A.O.C.B.**

None

The meeting closed at 19:53