

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

Notes of Meeting on Tuesday 10th September 2019, held at Scottish Parliament in Room TG20/21.

### **In Attendance:**

George Adam, MSP  
Stacey Adam  
Heather Armstrong, MS Society  
Laura Beverage, MS Society Scotland Council  
Jennifer Bryson, MS Society Council  
Prof Siddharthan Chandran, University of Edinburgh  
Angela Feharty, Revive MS Support  
John Finnie MSP  
Liam McArthur MSP  
Angela McCormack  
Iain Morrison, Revive MS Support  
Keith Robson, MS Society Scotland  
Morna Simpkins, MS Society Scotland  
Phil Skully, Coloplast  
Greg Stevenson, Roche  
Janice Thomson, MS Therapy Centre Lothian  
Chrissie Watters, Scottish MS Register  
Jill Williamson, Researcher

### **Apologies:**

Mary Douglas, MS Society Scotland Council  
Elinor Jayne, Sue Ryder  
Cat Johnson  
Lynda Kearney, Lead Specialist MS Nurse  
Judith MacSween  
Sarah Mather  
Rachel Morrison, NHS Western Isles  
Elizabeth Quigley  
Alastair Ross  
Angela Simonds, Celgene  
Steven Tait  
Karine Whitton

## **1. Welcome and introductions**

George Adam MSP, Convener

## **2. AGM – Election of Office Bearers:**

Keith Robson, MS Society, assumes chair for the AGM.

John Finnie MSP proposed George Adam MSP as Convenor.

George Adam MSP proposed John Finnie MSP and Donald Cameron MSP as Deputy Convenor.

**Convenor: George Adam MSP**

**Deputy Convenors: John Finnie MSP and Donald Cameron MSP**

George Adam MSP, resumes chair.

## **3. Matters Arising from previous meeting**

A letter has been sent out on behalf of the CPG to Health Improvement Scotland (HIS) regarding the need for condition specific standards. Still awaiting a reply. Keith Robson made the group aware that conversations are taking place between the Neurological Alliance of Scotland and HIS on this matter.

Other issues, such as Patient Pathways, will be addressed when the Minister comes to the next meeting to discuss the Neurological Action Plan.

Future CPG Collaborations – MS Society met with Carer's Trust Scotland to discuss a joint meeting around Carer's Week for the June 2020 meeting.

## **4. Update on Treatments and Research**

KR made the CPG aware that the MS Society is submitting a paper to the Health Technologies Group on 30<sup>th</sup> September. This is the first time MS Society has gone through this route for a patient group submission.

The Society will be make a Patient Group Submission to go the Scottish Medicines Consortium (SMC) for Ocrelizumab. Evidence Gathering is in process and the SMC meeting is on 3<sup>rd</sup> December.

## **5. Importance of Clinical Trials**

Prof Siddharthan Chandran of University of Edinburgh spoke to the CPG about the importance of clinical trials, especially within the Scottish context.

Prof. Chandran talked about the breakthrough that has come from the many research universities in Scotland and how there are so many opportunities to change the landscape to improve outcomes for people living with MS. He said that a more joined up approach is needed and the use of patient data would help researchers and others within the NHS.

Prof. Chandran invited the Convenor and others to visit the MS Society Edinburgh Centre for MS Research to see the work which they discussed.

## **6. The Pharma perspective of clinical trials**

Greg Stevenson, Roche, talked to the group about the importance of clinical trials. He explained about the process of the trials, why they are trialled for a long period to make sure it safe and will have benefit to those using the drugs.

A discussion took place on the need to get more medicines routinely available on the NHS in Scotland and how that may be achieved.

## **7. Stop MS Campaign**

Morna Simpkins, Director of MS Society Scotland, briefed the CPG on the upcoming Stop MS campaign. The Campaign launches in early October and includes an advert. The aim of the campaign is to raise £100 Million over a ten year period for MS research which aims to slow, stop and repair MS.

## **8. AOCB**

Iain Morrison proposed that the CPG has 'MS as a standard specific condition' as a standing item on the agenda in line with the aims of the group. This was agreed by CPG members.