

CROSS PARTY GROUP ON MULTIPLE SCLEROSIS (MS)

Notes of Meeting on Tuesday 27 March 2018, held at Scottish Parliament

In Attendance:

George Adam, MSP
Stacey Adam
Clare Adamson, MSP
Mhairi Coutts, Revive
Mary Douglas, Council Member MS Society
Angela Feherty, Revive
Daniel Lafferty, MS Society Scotland
Liam McArthur, MSP
Iain Morrison, Revive
Mairi O'Keefe, Leuchie House
Elizabeth Quigley
Keith Robson, MS Society Scotland
Niall Sommerville, MS Society Scotland
Greg Stevenson, Roche
Steven Tait, Council Member MS Society
Belinda Weller, Anne Rowling Clinic

Apologies:

Marion Butchart, Novartis
Merv Graham,
Elinor Jayne, Sue Ryder
Cat Johnson
Angela McCormack
Judith MacSween,
Morna Simpkins, MS Society Scotland
Janice Thomson, MS Therapy Centre

MEETING

George Adam MSP welcomed attendees and minutes of the previous meeting were agreed.

Update on Treatments and Research

Niall Sommerville talked about treatments currently being considered by the SMC and what may be in the pipeline over the coming year. He also talked about Daclizumab which had been withdrawn due to safety concerns bringing the number of disease modifying treatments back down to twelve for people with relapsing MS.

The Group had a broad discussion on recent media headlines concerning new potential treatments, in particular HSCT, and expressed its concern that people living with MS may be given false hope and spend their life savings on treatments abroad which may not be suitable to their circumstances.

Action:

- Agreed to write to the Minister to clarify the process by which individuals can access HSCT on the NHS in Scotland.
- Agreed to arrange a meeting with the Minister within the next quarter.

Leuchie House/QMU Partnership

Mairi O'Keefe, Leuchie House, gave a presentation to the CPG on the partnership working with Queen Margaret University to deliver person centred care for people with neurological conditions. Leuchie House had delivered more breaks than ever before; 6000 respite days for thirty five conditions.

The partnership with QMU was formally launched in March 2017 with the signing of a Memorandum of Understanding. They have extended the student placement scheme to include catering/hospitality, physiotherapy and nursing students. There is a clear aim that the next generation of Allied Health Professionals understand that delivery of care is not contained within acute care and NHS settings.

1st National Conference on Multiple Sclerosis for Primary Care in Scotland

Mhairi Coutts, Revive MS, updated the Group on the conference on 26th April at the Grand Central Hotel in Glasgow. Covering topics ranging from 'Self Management', 'Anticipatory Care Planning' and 'Supporting Patients to become involved in Research' the conference will also hear from Professor Siddharthan Chandran, Director of the Anne Rowling Centre. Tickets are only £15 and can be booked via:
www.eventsforce.net/msforprimarycare

MS Week

Keith Robson gave a short update to the Group on the preparations for MS Awareness week when we're going to get loud for MS research in Scotland. Unlike last year we will not have a stall in Parliament during the week, instead will be seeking meetings with MSPs to inform them of the work of the Society. George Adam is kindly hosting the Parliamentary Reception on 25 April the invitations to which have already been sent out.

Action:

- Keith requested that people share with him any activities which members of the Group are doing during MS Awareness Week so we can publicise them via social media.

Agree future meeting topics

- Agreed that the June meeting will be on the topic of MS Nurses. Mhairi Coutts and Jacquie Downs have both offered to help prepare the agenda.
- Agreed to investigate holding the September meeting jointly with the CPG on Epilepsy and invite the Minister to attend. Progress should have been made by then on the Neurological Action Plan to have that as the topic for discussion.

AOCB

None.

The meeting closed at 19:50