

# ME in Politics

## ME SCOTLAND UPDATE

So far 2012 has seen three meetings of the Cross Party Group on ME at the Scottish Parliament, as well as an evening reception held to mark ME Awareness Week in May.

### 19<sup>th</sup> January 2012 CPG Meeting

The January CPG meeting was largely taken up with consideration of how best to develop the new structure and way of working, with the establishment of six working groups:

- Lead Clinician / Centre of Excellence / Research
- Children and Young People with ME, including Education
- Educating and Training of General Practitioners
- Media and ME Awareness
- Health Care Needs Assessment 2010
- Welfare Reform,

Carol Flack gave a verbal report on the 25% ME Group member feedback exercise which had aimed to hear about the wishes and experiences of members in Scotland, effectively inviting round the CPG table people who are too ill to be able to attend in person. The aim was to give people with severe ME and their carers scope to raise the issues that matter to them. *Paper and e-copies of the feedback report are available from the 25% ME Group.*

### 21<sup>st</sup> March 2012 CPG Meeting

This was the first Cross Party Group meeting to take place under the new structure, whereby feedback from the Working Groups is circulated to CPG members in advance of the meeting, and prior to CPG meetings the nominated spokespersons from each of the Working Groups have a pre-meeting with the convener. I am presently acting as spokesperson for the Welfare Reform Group.

As well as feedback from the Working Groups and some further discussion as to structure – the convener stipulated that, unless required to make up numbers, she wished each CPG member to be involved in one working group only – the meeting focussed on social services and care issues, including reference to the 25% ME Group member feedback on this topic. I spoke to this item, and welcomed the opportunity as in my view consideration of these matters at CPG had hitherto been lacking.

*Member feedback on social services and meeting care needs is now available in a brief stand alone report. There are also separate reports on: (1) Experiences of the NHS and what we can learn from them; (2) Your illness - origins, course, and severity - and what works best for you; and (3) Access to Disability Benefits: Obtaining Medical Evidence*

### 8<sup>th</sup> May – Reception for ME Awareness Week

This event was organised at fairly short notice – for which a vote of thanks goes to our own Carol Flack, who as CPG secretary did the lion's share of the organising on this occasion. It was held in the Garden Lobby of the Parliament. The aim of the event was to raise MSP awareness of M.E. and in particular the lived experience of people with M.E. in Scotland.

Following an introduction and welcome by the Convener Mary Fee MSP, there were four speakers:

**Ms Jo Bluett**, who has ME and is involved in the Edinburgh ME Self Help Group. Jo has been a CPG member for some time and presently acts as spokesperson for the Lead Clinician/Centre of Excellence Working Group;

**Dr Gregor Purdie**, a GP with an interest in ME who is clinical lead for the Dumfries and Galloway NHS area and played a major role in the development of the Scottish Good Practice Statement for GPs. Dr Purdie is spokesperson for the CPG's Education & Training of GPs Working Group

**Mr Robin Partick**, the father of a very severely affected adolescent daughter. The Patrick family have had a harrowing time since the start of last year, when their previously healthy daughter became rapidly and severely unwell. This would be difficult enough to bear for any family, however they had faced a dearth of medical expertise and indeed their daughter had been labelled with 'Pervasive Refusal Syndrome' and the family treated with suspicion. Mr Patrick had no prior

experience of the CPG or speaking to MSPs and we would like to thank him for his courage and resolve in standing up to let parliamentarians and others in Scotland hear just how poor the response to people with severe ME can be in this country today. Mercifully he was also able to report that his daughter was beginning to show some signs of progress, albeit from a very low level.

**Ms Samantha Holt**, a primary teacher at Perth & Kinross Council, which has been in the vanguard of the use of Glow, the world's first national safe and secure online 'Virtual Learning Experience' Samantha's younger brother was diagnosed with ME in the first year of his secondary school, and she saw at first hand the devastating effect that a lack of formal education and social isolation can have. Traditional educational assistance, where local authorities arrange for home tuition at pre-arranged times, is singularly unsuited to children with ME due to unpredictable symptom flare ups and concentration issues. Glow holds much promise to allow young people with ME to access education to the best of their ability.

Seventeen MSPs attended or dropped in on the Cross Party Group's ME Awareness Week reception:

Neil Bibby (Lab)	Colin Keir (SNP)
Malcolm Chisholm (Lab)	Kenny MacAskill (SNP)
Bob Doris (SNP)	Fiona MacLeod (SNP)
Jim Eadie (SNP)	Siobhan MacMahon (Lab)
Annabelle Ewing (SNP)	Margaret McCulloch (Lab)
Mary Fee (Lab)	Jamie McGregor (Con)
Alex Fergusson (Con)	John Scott (Con)
Annabel Goldie (Con)	Paul Wheelhouse (SNP)
Mark Griffin (Lab)	

MSPs who sent apologies along with messages of support included Gavin Brown (Con), Roseanna Cunningham (SNP), Hugh Henry (Lab), Alison Johnstone (Green), Elaine Smith (Lab), Stuart McMillan (SNP), Duncan McNeil (Lab), Nanette Milne (Con), Margaret McDougall (Lab), Richard Simpson (Lab), Elaine Smith (Lab), and Nicola Sturgeon (SNP).

Simon Lawrence and myself attended on behalf of the 25% ME Group.

There is more coverage on the reception at the MERUK website - along with some pictures taken on the night. <http://www.mereseach.org.uk/cpgreception.html>

## **6<sup>th</sup> June 2012 - CPG Meeting**

This meeting followed on from the presentation on the 'Glow' interactive on-line learning resource at the Group's ME Awareness Week reception. Pupils from Collace Primary School along with their teacher Sam Holt and Gavin Pyott from Perth & Kinross Education and Child Services gave an interactive demonstration/presentation to the group.

Perth and Kinross council have been developing a Virtual Learning Environment (VLE) to provide educational support for children and young people who, for a range of reasons, are unable to attend school full time. The VLE project is hosted through Glow, the world's first national secure intranet for education.

There was also feedback from the Working Groups, and decisions on invites to speakers for future meetings. The Group's next meeting will be on the 19<sup>th</sup> of September, with a theme of 'Care in Scotland' and invites extended to the Health Secretary and the recently established Welfare Reform Committee at the Scottish Parliament.

You can find details of the Welfare Reform Committee at the Scottish Parliament at: <http://www.scottish.parliament.uk/parliamentarybusiness/CurrentCommittees/46339.aspx>

*By Helen Brownlie*