

ME in Scottish Parliament

Scotland: Holyrood Update

Cross Party Group on M.E.

Since the last edition of the quarterly there has been a further – and what proved to be final – meeting of the Cross Party Group on ME at the Scottish Parliament. After over ten years of effort on various fronts over the course of three Parliaments, friends made, and bonds developed, this is both a sad and - in view of the circumstances around closure - we regret to say a welcome development.

At a CPG meeting on September 19th 2012 the Cross Party Group on ME was asked to vote on whether to be a Cross Party Group on ME or a Cross Party Group on ME and range of fatiguing disorders. This vote took place at the behest of the convener and under threat of her resignation if the vote went in favour of ME.

The choice put before the Cross Party Group on ME was:

To focus our endeavours on the WHO ICD10 G93.3 neurological disease ME or instead, choose to proceed under the umbrella term ME-CFS to include a spectrum of fatiguing conditions?

These options stemmed from a sub group meeting at which the convener Mary Fee MP had been present. We understand that at this meeting the convener was unsympathetic to the view that the Cross Party Group on ME should be pressing for the establishment of a Centre of Excellence that would clearly and specifically focus on M.E. It had emerged that the sub group was divided on this point, with Lesley Scott, (TYMES Trust) Jane Giakoumakis (Lanarkshire ME Support), and Margaret Williams (ME East Kilbride) keen to see the CPG pressing for a Centre of Excellence on ME. Rather than take this specific matter to the full CPG for consideration, the convener attended the next sub group meeting. When the impasse remained she remitted Lesley to present a basis for the CPG to vote - *not* on this specific issue but on the Cross Party Group's *remit* -reflecting the discussion at the sub group.

Lesley's Scott's paper with the above voting options was circulated nine days in advance of the meeting. The CPG secretary had been led to anticipate that a paper by the convener would also be circulated. This has never materialised.

At the CPG meeting the vote was introduced by the Convener as originating from a view on the part of some members that no one with a CFS diagnosis should be represented by the CPG on M.E. I for one felt my jaw just about hit the table at this point. Clearly Mary Fee had a very poor grasp of the situation. However she did *not* propose any discussion, rather the reverse, and on we went with the vote.

The vote went resoundingly in favour of M.E. Just four votes were cast in favour of the 'spectrum of fatiguing conditions' option. It is notable that the convener subsequently communicated that this option "*would appear to broadly follow the existing remit of the group*" [message to Lesley Scott]. This came as a surprise to all of us who had always assumed that a Cross Party Group on M.E. meant just that.

Sad to say that neither of the two major national ME charities supported the ME option at the meeting, choosing to abstain on the vote. Neither did MERUK stand up for ME.

Nonetheless votes for the group to continue as a CPG on ME outweighed the votes for the 'fatiguing disorders' option and abstentions combined. Curiously the majority, who *did* stand up for ME and against the fatigue lobby – including the 25% ME Group, the TYMES Trust, and many local support group representatives - have since variously been described in as a 'faction' and 'certain individuals'.

Lesley Scott of the TYMES Trust in Scotland was close to the action throughout. She has commented eloquently on the emerging scenario regarding MSPs perspectives:

The MSPs are indeed very frustrated with us, but why are they frustrated? It is a frustration that is wholly fed on the fact that we will not compromise on ME being a neurological disease and accept it as part of a fatiguing spectrum, thus allowing the 'progress' they so desperately want at the expense of patient care.

The crashing irony is that this same CPG meeting had just been provided with feedback from the working group on GP education. The situation is hair curling: ME is *occasionally* mentioned in the curricula of the medical schools in Scotland, but always in the same breath as chronic fatigue syndrome, which in turn is viewed as amounting to chronic fatigue due to somatisation - therefore a 'somatic syndrome'/'functional disorder' *etc etc...* It could not have been clearer that the situation on the ground is dire: confusion reigns, much to the detriment of people with M.E.

Following the meeting many felt that the best thing in the circumstances would be if Mary Fee were to stand down as convener, as she had vowed to do if the vote went in favour of M.E. However Mrs Fee attempted to hang on and oversee a further (unspecified) vote. In the event her failure to adhere to the outcome of the vote was referred by a group of concerned CPG members to the Standards Committee, following which she and the vice conveners resigned.

We have since been treated to the eulogising of Mary Fee as an MSP who was exemplary in fostering co-operation. This is

extremely hard to take in the circumstances. For example, Mary Fee had consistently turned a deaf ear to all attempts at communication from us, including an invitation from Simon Lawrence to visit the Troon office and hear about our work. If she had had the courtesy to engage then perhaps she would not have revealed such a lack of understanding of what our perspective actually is. We are similarly less than impressed by her record in responding to individual people with M.E

ED COMMENT: Several papers relating to the events at Cross Party Group are available on the 25% ME Group website.

The 25% ME Group would like to express sincere thanks to our Scottish Information Officer Carol Flack, who took on the role of secretary of the Cross Party Group at the beginning of the year and steered a highly competent and professional course throughout what proved to be a difficult period.

Carol is that rarity – a healthy person willing and available to work to secure the best for people with ME. However, she also has to earn a living! The 25% ME Group would love to be able to retain Carol's services. But we need funds. If you might be interested in supporting us to employ Carol on time limited projects to the benefit of people with M.E. in Scotland then please contact Jane Giakoumakis on 01698-817114. *Even a small monthly pledge for the period of a year could help us reach the target threshold where it becomes meaningful to engage Carol.*

liME to Circulate GP info packs

In a further irony, Invest in ME were to have attended the November meeting of the Cross Party Group on M.E., to speak about their sterling efforts to make a reality of a Centre of Excellence for biomedical research into M.E. Following the demise of the CPG Invest in M.E. has decided to make 25 copies of the liME GP information pack available for Scotland. The idea is to help the situation in Scotland as best they can and that education is the best way to progress and improve the way people with ME and their families are treated.

Helen Brownlie