

## **A New Secretariat for the Scottish Cross Party Group on M.E. is Announced**

1st December 2011

We are pleased to announce that the 25% ME Group will be taking over the secretarial duties on the Cross Party Group on ME in Scotland, following the CPG AGM on the 1st December 2011.

We would like to thank AfME and especially Susan Webster, for their service to the Group and thank them for welcoming us into this new role.

The new worker that is employed by the 25% ME Group, will be Carol Flack...

Carol is originally from Northern Ireland but has been living and working in Scotland for more than 20 years. She has a strong background in health inequalities and anti-discriminatory practice gained through working in a wide range of projects in London and in Scotland. She first moved to London in 1984 to study Psychology and at the end of her degree she moved to Aberdeen and then Edinburgh to work as a residential volunteer.

Carol is also a graduate from Strathclyde University (person-centred counselling) and the University of Edinburgh (advanced professional studies), choosing to study part-time while working so that her learning has always been grounded in her practical experience and vice versa. Her professional background is in homelessness, mental health, counselling, addictions, disability, groupwork and training – basically she is interested in people and in what can be done to improve the quality of life of those most disadvantaged in society. In 2010-2011 she managed a project focusing on issues around disability, caring and 'voice' for those with diverse communication support needs.

Carol has worked primarily within the voluntary sector but has also been employed as a freelance consultant and trainer with a variety of agencies and organisations including local authorities, health boards, social work and education departments. She is delighted to join the 25% ME Group to support the work of the Scottish Parliament's Cross Party Group (CPG) on ME and in her role as secretary will be keen to assist the CPG to work effectively to address the issues which impact on people who have the severe form of ME and those who care for them.

Carol is committed to accepting this role for the coming year. However it is important to understand that the responsibility is vested with the 25% ME Group, just as previously it was vested in AfME

Members in Scotland will know of Carol through her recent work on a member feedback study that we hope will inform the work of the CPG in the coming session, helping ensure that the voice of people with severe ME in Scotland is heard.

However by the time Cross Party Group meets again in the New Year this work will have been completed and Carol will have been offered a fresh contract specifically to carry out the secretarial duties. We hope that this will help inject a note of independence as the secretary will have duties only to the CPG and no additional 25% ME Group duties.

We hope that we will bring the professionalism, dedication and passion to this new role, as we do to other activities within the ME community

Thank you to all those that have encouraged and supported us in undertaking this work

Simon Lawrence

Chairman

25% ME Group

[www.25megroup.org](http://www.25megroup.org)

Other Useful Links:

Scottish Parliament website: <http://www.scottish.parliament.uk/>

Information about Cross Party Groups: <http://www.scottish.parliament.uk/msps/1696.aspx>

### **Looking Forward ....**

The next meeting of the Cross Party Group on ME will be held on the 19th of January. In the coming year issues will be considered by sub-groups between meetings, with a spokesperson from each group nominated to feedback the group's views to the MSPs. Pre-meetings between these spokespersons and the conveners will replace the previous arrangement, whereby a committee met two weeks in advance of CPG meetings to discuss progressing CPG business.

A well as providing member feedback (see above) to help inform the work of the CPG, we have obtained 'an appeal for appropriate care', a testament from Kay Gilderdale regarding the terribly adverse and long lasting impact on her daughter Lynn pressure to do things that were beyond her while in hospital 'care'. Kay says: We watched as our daughter, under the care of those who said they could cure her, lost the ability to do almost anything. We wanted to believe what they said so much that we held on, even when we saw her deterioration, but sixteen days after her admission, we knew we had to take her home... she was in a pitiful state. She could do nothing for herself and needed 24 hour total care."

Kay Gilderdale's plea for appropriate care was circulated at the September CPG meeting . We hope that her words will make an impact on the MSPs and other members of the Cross Party Group, particularly when attempting to bring pressure to bear in securing better care for people with ME via the Health Care Needs Assessment.

Published last year, this presents both pitfalls and opportunities. One clear pitfall lies in the oft repeated references to 'rehabilitation' including: "there was a need not only to make use of the rehabilitation services and the wider range of community and specialist services to support people with ME-CFS, but also to ensure that such services had sufficient capacity to provide appropriate care."

The experience of Lynn Gilderdale, and countless others who suffer from severe ME, is testimony to the fact that it is not lack of capacity in 'rehabilitation' services that is the problem. It is a gross substantive disjunction between the nature of these services and what constitutes appropriate care for a person with ME. We are aware that many members of the 25% ME Group only became severely affected after being exposed to ill advised attempts at 'rehabilitation'.

Some have welcomed the proposal to set up multi disciplinary teams led by a consultant. However the identification of 'rehabilitation medicine' as one of the potential specialties from which such clinical leads might be recruited (the others being neurology and infectious diseases) is regrettable.

We have posted Kay's appeal on the 25% ME Group's website to help members throughout the UK make the case for more appropriate care. It has also been passed to members of the APPG at Westminster (see below).

By Helen Brownlie, Representative in Scotland,

25% ME Group