

## **The end of the Cross Party Group on ME : by Tymes Trust**

The Young ME Sufferers Trust (Tymes Trust) values its reputation. In the aftermath of the demise of the Cross Party Group on ME in the Scottish Parliament, EdMesh published a version of the events which in our view misrepresented not only the facts but also the actions of the Trust. They granted the Trust a right of reply to put the record straight but then withdrew it.

Let us be clear. The Convenor of the Cross Party Group initiated a vote, requested the Trust to draw up the voting options, and then (in writing) approved the suggested wording, commenting that the options 'appear clear'. It is dishonourable of EdMesh to imply bias on the part of the Trust after the vote did not go the way they favoured. And any suggestion that we would not wish to see all patients appropriately helped is disgraceful.

It is vital that we now reflect with accuracy on what really happened in the Scottish Parliament, and on the opportunity which Scotland lost that day, especially in light of subsequent events.

A split in opinion existed within the working group considering a centre of excellence for ME and a lead clinician. Some wished to see a specialist 'ME' clinic (such as those formerly run by Dr Elizabeth Dowsett and Dr Abhijit Chaudhuri) rather than a further proliferation of 'ME/CFS' fatigue clinics, with their usual emphasis on therapists rather than knowledgeable doctors who understand the discrete neurological disease myalgic encephalomyelitis with its tendency to severity and chronicity.

The meeting of the 29<sup>th</sup> August had been arranged specifically for consultant neurologist Dr Abhijit Chaudhuri to attend and inform the debate with his vast experience and authoritative knowledge on the subject. Dr Chaudhuri (initially under leadership from Professor Peter Behan, and subsequently as lead clinician himself) had run an ME clinic in Glasgow at the Southern General Hospital Neurology Department. Patients were referred here from their GPs for diagnosis, and if they were found not to have ME but, for example, chronic fatigue, those patients were referred onwards to appropriate services such as psychotherapy or other appropriate treatment. Patients were also brought into hospital for further testing if required. Drug trials were conducted and they had a caseload of research patients they were able to pass to other researchers. ME was properly provided for, and no category of patient was ignored.

Dr Chaudhuri is outspoken on his belief that ME and CFS should be separated:  
*'Unless neurologists start to take an interest, and segregate ME out from the rest of chronic fatigue patients, it will be very hard to try and develop our understanding, research, or talk about new treatments...'* (Cathcart ME Support Group Meeting, June 2010). Unfortunately, Dr Chaudhuri was unable to attend the meeting on the 29<sup>th</sup> through work commitments; some group members tried to have the meeting postponed to another date, but it duly went ahead on the 29<sup>th</sup> with CPG convenor Mary Fee in attendance.

By the end of the meeting, the group remained in deadlock and Mary Fee took the decision that the matter should therefore go before the full CPG in order to find some

resolution. Later that day our Scottish representative received a telephone call from Carol Flack, CPG Secretariat, on behalf of Mary Fee requesting that Tymes Trust prepare the voting options for the full CPG at the next meeting, the 19<sup>th</sup> September.

On the 9<sup>th</sup> September the Trust's suggested wording was emailed to Carol Flack who then forwarded it immediately to Mary Fee for approval, prior to issue with all other CPG documentation on the 10<sup>th</sup> September. This was then sent, in its entirety, to all CPG members.

Confirmation that Mary Fee herself approved the voting options as accurate and reflective of the debate can be seen from her e-mail of 25<sup>th</sup> September 2012: 'The options circulated appear clear and voting option 2 would appear to broadly follow the existing remit of the group.'

Democracy is the principle on which our whole society is based. The votes cast were overwhelmingly in favour of a specialist ME clinic, and it is hard to justify why this democratic vote was not accepted, whether it was popular amongst the 'powers that be' or not. Given that a vote was neither proposed nor overseen by the Trust, or by patient groups, but by Mary Fee MSP, who was elected under the principles of democracy, we consider that patients in Scotland have been badly let down.

It is important to remember that the 'Myalgic Encephalomyelitis – Adult & Paediatric: International Consensus Primer for Medical Practitioners 2012' states that lack of knowledge has allowed 'CFS' to persist 'causing a web of confusion'. It goes on: 'We believe this is the foremost cause of diluted and inconsistent research findings, which hinders progress, fosters scepticism, and wastes limited research monies.'

We would also refer readers to the 25% Group's own account of these matters.

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