

I have enormous respect for all the work that Invest in ME are doing to promote research into ME/CFS and have always supported them. It was with some disappointment that I read their response to the question on their Facebook page asking why they were not members of Forward-ME.

I invited them to become members from the very beginning and I understood that circumstances prevented them sending a representative to Forward-ME meetings. To say that we did not discuss their questions is incorrect. Their views on the name for the illness were fed into our initial discussions and we agreed that it should be ME/CFS – a term that has been used consistently throughout our minutes unless quoting from other documents. We have frequently discussed misdiagnosis and possible solutions, including the use firstly of the Canadian and then the International Consensus document as a means of defining the symptoms. That there are varying views on NICE has always been clear and we have agreed to differ. There are some parts of the NICE Guidelines that can be useful in some circumstances.

Over the years we have been addressed by several Government Ministers and Civil Servants who have responsibility for health, education, social services and social security and have been able to transmit our concerns about the way people with ME/CFS are treated. Whilst our achievements may have been limited, our views as a group are acknowledged and we are consulted on a regular basis.

The 'Principles of working' for Forward-ME state that 'We seek to maximise consensus but respect those who have differing views'. It became apparent that IiME was having some difficulty in accepting this from their Email to me of 23 March 2009, as indeed from subsequent correspondence. I wrote to IiME following our meeting on 8 July 2009 to say that it was clear that they were uncomfortable working with some of our members and to ask whether, in the circumstances, they wished to continue with their membership. I had no response to my letter. The result is recorded in the minutes of 24 November 2014.

I would welcome IiME back to Forward-ME if they were prepared to work with all members of the group without prejudice. Unless we all pull together we will never succeed in achieving our objectives.

Margaret Mar

Chairman, Forward-ME