

## **ONE CLICK TOO FAR ?**

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In the interests of accuracy it has become necessary to set the record straight about various unwarranted and potentially damaging accusations originating from Jane Bryant and Angela Kennedy (the two women who run “The One Click Group”) that are being publicised on the internet against Drs Vance Spence and Neil Abbot of the ME charity MERGE. In essence, Drs Spence and Abbot are accused of “colluding” with psychiatrists and of sitting on their tainted hands by not “whistle-blowing” about recent draft Guidelines from the Royal College of Paediatrics and Child Health that purported to address the issue of “CFS/ME” before the final report was published.

Curiously, neither Ms Bryant nor Ms Kennedy obtained an available copy of the RCPCH draft Guidelines, nor did they submit any critique during the consultation period. Had they done so, they themselves could have chosen to “whistle-blow” if they believed such a course of action to be the most effective way forwards.

In refuting the allegations posted by One Click about MERGE, in his post on Co-cure of 7<sup>th</sup> January 2005 (“MERGE and the Royal College of Paediatrics and Child Health Guidelines 2004: a clarification”) Neil Abbot succinctly and factually summarised the involvement of MERGE in the RCPCH Guidelines. His response effectively demolished the spurious accusations made by One Click, making as it did valid and critical points about the RCPCH document with which no-one in the ME community could credibly disagree (namely, drawing attention to key concerns such as: a) over-emphasis on non-curative, poorly evidence-based psychosocial management strategies b) the extremely problematic extrapolation of trial results from adult ME/CFS patients to children, particularly in respect of psychosocial techniques c) the presence in the draft guidelines of thinly-veiled invitations to uncover psychological dysfunction without clearly-defined criteria for such psychiatric referrals and d) the need for the Guideline Development Group to take into account ALL the available evidence).

Inexplicably, One Click refused to accept the validity of this and MERGE continues to be subject to “threats”: “The Jan van Roijen Newsletter is carrying Neil Abbot’s post on Co-Cure (again), in which he has attempted to deny MERGE’s collusion in keeping the contents of RCPCH document out of the public domain until its official publication, and discredit One Click’s actions in making this collusion public. If MERGE’s attempt to discredit One Click persists in any way, further evidence will be placed in the public domain. Some sacred cows are just that – cows. And in particular it would seem, this one” [10<sup>th</sup> January 2005].

On the same date, this was expanded to include the following: “This is getting to the stage where enough is enough. I think that the One Click chain has now been yanked just that once too often over this issue. It is as if MERGE is casting two Mothers of sick ME/CFS children as the villains of the piece. There is this great old adage: Do unto others as you would have them do unto you. I am starting to think that it is high time that we did precisely that. It would seem that certain individuals and organisations are trying to provoke us. Perhaps they should pause to consider just what the consequences of such provocation might be”.

It is to be welcomed that Ms Bryant's own 13 year old son has recovered sufficiently to be allowed to play outside in a nearby park without his mother's presence and is back at school; such being the case, Ms Bryant is to be commended for her continued commitment to the plight of all children and young people with ME/CFS in the UK. Sadly, however, One Click's "ME activism" seems increasingly to consist of little but attacks, abuse and threats.

Most people will realise firstly that as a free-lance journalist whose stated target audience is the popular press, Ms Bryant's background is not in either science or medicine and secondly that she has no working knowledge or experience of the system that governs applications for funding that prevails in the UK (especially of the way in which the Establishment controls such applications) or of the fact that such funding is only allocated if the project is in line with current Government policy.

Whilst some of the issues raised by The One Click Group do indeed need to be raised and addressed in a mature and reasoned manner, it is regrettable that One Click chooses to do so in such a vitriolic, emotional and immoderate way that reveals not only a lack of factual knowledge but a lack of judgment and understanding as well. It has become inescapable that One Click attacks not only charitable organisations (which as publicly accountable bodies are required to answer legitimate criticism), but also individuals within the ME community (who have no such obligation or corporate protection).

For One Click to continue to attack so publicly those in the UK who are doing the most to unravel the maze of contrived confusion that is presently ME/CFS is hardly logical or helpful to the cause.

Without doubt, there is legitimate concern throughout the ME/CFS community about the politics currently surrounding ME/CFS that result in the constant denial and dismissal of relevant evidence of an organic pathoaetiology by those who have powerful vested interests in such tactics of denial. There is no doubt that this has a detrimental impact upon both child and adult sufferers of ME/CFS and their families and that it needs to be exposed and addressed.

It is also the case that, flowing from this prevailing situation, there is deep concern about the perceived failure of the major patient-based ME organisations to speak out robustly and repeatedly against such connivance, especially those organisations whose job is to promote and protect the best interests of their members, which must surely include speaking out against the implacable determination by certain psychiatrists to claim "CFS/ME" as a psychosocial disorder when this flies in the face of so much international reputable published evidence to the contrary.

However, MERGE is not such an organisation. It does not have members: it does not represent patients per se and has no formal role as a voice of patients. Its primary purpose is as a research group, aiming to raise the amount of good-quality biomedical investigations into ME. Solely in order to help inform current debate, it has on occasion produced highly acclaimed documents (available on the MERGE website: <http://www.mererearch.org.uk>) such as "Unhelpful Counsel", "Standing Up for ME" and "Severely Overlooked by Science" which includes a critique of the FINE trial.

The aim of MERGE is to succeed in establishing the aetiology of ME/CFS. In its comparatively short existence its track record has been astounding, not only in the impressive

calibre of its scientific research but in the number of its studies that have been accepted and published in high impact professional journals. If it achieves this - working by necessity within the constraints of the prevailing system - it will destroy for ever the psychiatrists' currently dominant belief about ME/CFS (namely that it is a psychogenic disorder best managed by compulsory exercise and by psychotherapeutic techniques designed to correct the "dysfunctional" and "aberrant" beliefs deemed by these psychiatrists to perpetuate the disorder).

It is apparent that The One Click Group has no understanding of this reality. Since its emergence in October 2003, numerous organisations and individuals have been targeted for not agreeing to its demands. One individual received at least 66 emails from One Click in just a few weeks. Even the Co-cure list-owner and moderators have been attacked and abused by One Click. MERGE is only the latest in a long line of targets for One Click's venom.

One Click's actions have caused a former supporter to write in the following terms: "Jane's reaction worried me (especially) the abusive manner in which she addressed the issue. It seemed to me that she employed the very tactics (including intimidation) which she claims have caused her personally a great deal of distress. I am now in the position of not knowing how much of Jane's authorship I can believe".

For the avoidance of doubt and so that people can make their own informed assessment, here are some actual quotations about other targeted individuals sent by One Click:

When in May 2004 Doris Jones MSc (a long-time campaigner for ME and Co-Editor of the respected Environmental Issues Forum) did her best to curb Ms Bryant's clearly immoderate behaviour by tactfully suggesting that it might be wise not to adopt "a slightly over-enthusiastic and possibly hasty approach (as) people in authority are much more likely to listen to you and take you seriously if you present your case guardedly. If you go 'over the top' or allow emotional aspects to dominate your arguments, you could be in serious danger of not achieving your goal", she received the following response from Jane Bryant, which was circulated to others: "I think you are one of the rudest women that I have ever met. You are just too much Doris. You are arrogant, destructive, rude, patronising and ill informed. You are an amazing old bird Doris, but from your correspondence you show yourself to be a pretty unpleasant one. Come off your high horse old girl".

At 21.28 hours on 2<sup>nd</sup> October 2004 Jane Bryant posted the following on One Click about a valiant and very sick ME campaigner: "Tom Kindlon, the Irish bunny, is at it again on the internet. Tom Kindlon, why don't you just f.k off to Ireland and leave us alone? Just do your thing in Ireland and leave us alone, Tom Kindlon? Because one thing I promise you Tom. The next time that you attempt to get media exposure of the ME/CFS issue, ONE CLICK will take great delight in ramming your written sentiments right down your Irish throat in relation to the PACE trial". At 23.48 hours that same evening, Jane Bryant sent another item from One Click: "Bugger off to Ireland, Tom and leave us alone. Our children are at stake here and we are not impressed with your extremely flawed self serving prose".

Unsurprisingly, such undeserved and offensive outbursts caused the recipient (who in fact lives in Ireland) untold dismay and would doubtless have afforded much self-satisfied merriment to those who wish to see the ME advocacy lobby weak and divided.

Another target of One Click's vitriol has been the stalwart but extremely sick Dutch campaigner Jan van Roijen who at great personal cost runs the Help ME Circle when he is able to do so. Initial endless importuning for help with the setting up of One Click soon descended to depths of rudeness amounting to little short of cruelty: "Jan you have done so much already. And I hesitate to ask you for more. But Jan, I do not know where else to turn. Can you help me please? Can I ask your advice? Could I please draft the next post that I plan to put up on the One Click Protest group and email it to you for your consideration first? [13<sup>th</sup> October 2003: 09.32 hrs]; "Hello again Jan. I am sorry to take up your time. But I do not know what else to do than to ask your advice" [13<sup>th</sup> October 2003: 13.23 hrs]; "You are a truly great man in my book. I may be the founder of the One Click Group but you my friend are its inspiration [15<sup>th</sup> October 2003]; "Jan, I am sorry to have to ask you again. But is any help going to be forthcoming with One Click or not? I need to know now Jan. I really do. I respect you Jan. I consider you to be my ME mentor" [24<sup>th</sup> October 2003: 21.57 hrs]; "I gather from your silence Jan that the cavalry is not coming to assist myself and my twelve year old son with One Click any time soon. So Jan, me and Ben have decided to do One Click ourselves. Utterly." [26<sup>th</sup> October 2003: 16.18 hrs].

Ironically, on 7<sup>th</sup> October 2003 Ms Bryant wrote to Jan van Roijen: "In the UK, the bitterness, mistrust and constant desire to complain rather than try to do good runs deep".

Seemingly forgetful of what she had written, Ms Bryant now sends invective missives to Jan van Roijen: "What a shame that you have chosen to come out of retirement....Didn't know that you were on the side of the psychiatrists" [30<sup>th</sup> September 2004]; "Was your intention to make us work hard to rebut (your) information on this issue and deflect our purpose for this day, (the very day that) White was to speak on the PACE trial in London? A copy of this email has gone to the handful of shakers and movers in the ME/CFS field just to keep them apprised (sic) that whereas the JvR Newsletter was in the very distant past something to conjure with, now it is clearly under new management. Shame on you Jan. The greatest there is." [1<sup>st</sup> October 2004].

In the recent past, Ms Bryant has been criticised in the following terms:

"Why is it that every time you put forward a view it is accompanied by offensive words about somebody or something? Your diatribes are prolix and contain numerous omissions, distortions and falsifications. Others are capable of making the same points without resorting to the vilification of people or organisations. Why not you? It's not your views that are objectionable but the offensive and abusive manner in which you promote them. What is it about your personality that produces this craving for conflict? What has been the result of all your frenetic activity? All the destructive comment, all the abusive language, all the fabrications that you peddle over the Net? Zero. Why? Simple. Because you have done an absolutely superb job of alienating anybody and everybody with any knowledge or influence in the ME field. When you do make a good and sensible point you add such a large dose of vitriol that no one gives it any credence. You have achieved precisely the reverse of what you intended. No-one, but no-one, takes the slightest notice of your views on ME/CFS or anything else. When will you wake up to the fact that you DO NOT represent the ME/CFS community. This letter is addressed to Jane Bryant, self-appointed ME community spokesperson (and) serial email abuser".

Ms Bryant described the above mail as “hate mail abuse” and affirmed that it would be sent to “the media”, yet she seems to believe that One Click has an inalienable right to publish unjustified abuse about others.

Such an approach is not the way to gain either respect or credibility for the ME cause and might be ultimately playing right into the hands of those in the psychiatric lobby (who are known to lurk the ME sites) and of all those whose aim is to prevent serious research and investigation into ME/CFS. But maybe that has been One Click’s intention all along? Why else would One Click give master-classes in destructive emotion?

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**Information about One Click**

Margaret Williams

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