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THE SHEPHERD QUESTIONS AND THE MEA

For many weeks, Dr. Shepherd has refused to answer questions posed to him by both members of the MEA and by the wider ME/CFS community. Dr. Shepherd has campaigned on the internet for change within the MEA; that full and frank dialogue must take place. Unfortunately, this has not been forthcoming to date.

For many years Dr. Shepherd was Medical Director/Adviser for the MEA.

I would ask you please to consider the questions and facts below.

1. Precisely what was Dr. Shepherd's involvement in the 1990 ME/CFS Cambridge Symposium?
2. Why did Dr. Shepherd sanction the psychosocial stance of the Myalgic Encephalopathy Association (MEA) for two years or more as Medical Director/Adviser of this charity before he spoke up?
3. Why has Dr. Shepherd refused to provide to date the transparency, accountability and required information in regard to the MEA doings - both past, present and future prospects - that he campaigned for so assiduously out on the internet so that MEA members (both extant and potential) and the wider ME/CFS community can make an informed decision as to whether to support this currently failing charity or not?
4. On what basis does Dr. Shepherd liaise with Professor Simon Wessely (psychiatrist) as has been illustrated and evinced by the statement issued by the previous MEA Chairman, how often and why?
5. What is Dr. Shepherd's precise involvement with Action for ME (AfME), over and above the work that he already does for AfME/Westcare and his work with Colin Barton (AfME Affiliate) of the Kent & Sussex ME Group over the production of his new Guidelines?
6. Precisely what discussions have taken place between Dr. Shepherd and AfME regarding the sharing of premises between the MEA and AfME and the possible merger of the two charities amongst other issues? What was said and proposed during these discussions?
7. It is highly possible that the MEA charity will have to close due to the lack of income. The other ME/CFS adult's charity in the field, AfME, is currently the subject of a public investigation due to the concerns raised over its psychosocial stance, policy and workings that are not condoned by subscribers. AfME has not held an Annual General Meeting that has involved its subscribers for the last eight years, since 1996. AfME subscribers have been completely disenfranchised. Why does Dr. Shepherd refuse to rule out the possibility that the MEA will be merged with AfME? Is this because Dr. Shepherd hopes to gain lucrative employment as a

Medical Adviser from AfME in the future - a charity that he is currently working with part time already?

8. Why does Dr. Shepherd, together with the psychiatric lobby, continue to sanction, promote and employ the term Myalgic Encephalopathy that has no disease classification anywhere in the world over and above the nomenclature of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome that has international neurological disease classification under ICD 10 - G93.3?
9. Does Dr. Shepherd not recognise that to change Myalgic Encephalomyelitis (ICD 10 G93.3) to Myalgic Encephalomyelopathy to please some doctors - the majority of them psychiatrists - is dangerous and not in the interests of patients? Especially since this is precisely what occurred when the 1996 Royal Colleges report came out with the subsequent labelling of CFS (with Myalgic Encephalomyelitis being subsumed under this umbrella term) as a mental disorder by those very same psychiatrists?
10. Why is Dr. Shepherd as Trustee of a supposedly patient focussed organisation not only colluding with the psychiatric lobby in their adoption of the term Myalgic Encephalopathy to the detriment of patients, but making the most determined of efforts to ensure that the psychiatric lobby and the Department of Health adopts it?
11. Why does the very mention of Dr. Shepherd's involvement with HealthWatch and Professor Wessely result in a blizzard of letters and threats of litigation? If Dr. Shepherd has nothing to hide, why is this issue so clearly very sensitive?
12. Why do any comments or questions posed in relation to the conduct of Dr. Shepherd both in the past and in the present, immediately result in a blizzard of litigation threats?

BACKGROUND INFORMATION

- Dr. Shepherd took the personal initiative to have the Myalgic Encephalomyelitis Association renamed as the Myalgic Encephalopathy Association.
- The MEA went down the psychiatric/psychosocial route and lost all the confidence of its members. It has insufficient funds and not enough Trustees to currently continue operating.
- As Medical Director/Adviser of the MEA, Dr. Shepherd proactively sanctioned and promoted the MEA and therefore the psychosocial stance of this charity for many years.
- At the time that his hours and income were cut, not before, Dr. Shepherd then campaigned on the internet and called for change and a palace revolution within the MEA. His manifesto stated that if he was elected Trustee, the affairs of this charity would in the future be conducted with transparency and accountability as is required by the Charity Commission of England and Wales.
- At the MEA Annual General Meeting (AGM) before Christmas, the MEA Chairman Anne Campbell resigned together with other of the Trustees. Val Hockey, the CEO, was made redundant.

- Dr. Shepherd was then appointed a Trustee, Mr. Chris Ellis was appointed the new MEA Chairman, two other new Trustees were appointed also and two remained from the existing Board. No full and frank disclosure of information was given to MEA members at that time.
- On the 26th January 2004 the MEA Chairman issued a statement that clearly illustrated that the Board of Trustees was and still is in complete disarray, that the financial affairs of the charity are in chaos, no cogent information was forthcoming and that Dr. Shepherd was seeking to hold formal talks with the charity Action for ME (AfME). This news was greeted with considerable dismay by MEA members and the wider ME/CFS community because AfME has also lost the confidence of its subscribers and is currently undergoing investigations by the Charity Commission. AfME is also the subject two written questions posed in the House of Lords.

See:

<http://www.bryantpr.plus.com/Chris%20Ellis%20Statement%2026.1.04.txt>

- On the 27th January 2004 Dr. Shepherd issued a rebuttal statement to counter the statement made by the MEA Chairman the previous day.

See:

<http://www.bryantpr.plus.com/The%20MEA%20-%20A%20New%20Start%20-%20The%20Shepherd%20Statement%2027.1.04.txt>

- On the 18th February 2004 the MEA Chairman issued a statement to say that he has resigned. He cites irreconcilable differences between the Trustees; that he cannot work with Dr. Shepherd; that Dr. Shepherd liaises frequently with Professor Simon Wessely (psychiatrist); that Dr. Shepherd has suggested that as the MEA Chairman, he should do the same; that Dr. Shepherd is motivated for his career interests; that Dr. Shepherd has been in touch with AfME regarding the sharing of premises between the MEA and this discredited charity; that a formal meeting between AfME and the MEA had been suggested by Dr. Shepherd presumably to discuss a merger between the two charities.

See:

<http://www.bryantpr.plus.com/Chairman%20of%20MEA%20Resigns.txt>

- On the 22nd January 2004 in the House of Lords debate led by the Countess of Mar, the classification issue of Myalgic Encephalomyelitis/Chronic Fatigue syndrome is brought into high relief. The Health Minister Lord Warner is forced to subsequently apologise over the fact that CFS has been erroneously classified as a mental disorder by the WHO King's College Collaborating Centre (Home of the Wessely School of Thought) and that he has been incorrectly briefed. The WHO Geneva issues information that Myalgic Encephalomyelitis/Chronic Fatigue Syndrome is confirmed as a neurological illness under ICD 10 – G93.3.
- The WHO Collaborating Centre King's College is forced to issue erratum slips and make website amendments due to their mal classification of CFS as a mental disorder.

- Instead of welcoming this triumph for the patient community, Dr. Shepherd, the Myalgic Encephalopathy Association Trustee, shifts his focus away from the MEA difficulties and goes into high gear over his promotion of the term Myalgic Encephalopathy that has no disease classification whatsoever. Dr. Shepherd's friends and colleagues in the psychiatric lobby with whom he liaises greet the ME-opathy term with high delight and begin to use it in the media. Dr. Shepherd's rationale for adopting the ME-opathy term is that the use of this term makes his friends and colleagues in the psychiatric lobby feel more comfortable.
- Dr. Shepherd then announces in public that the term Myalgic Encephalomyelitis with its international neurological disease classification is considered "ridiculous" by many of his medical colleagues despite the fact that this is the term that is used by expert clinicians who work in the field worldwide including Dr. Shepherd's previous mentor, Melvin Ramsay and the ME/CFS community both in the UK and worldwide.
- Massive dissent in the ME/CFS community is caused by Dr. Shepherd's insistence that the term ME-opathy be adopted in order to make his friends and colleagues in the psychiatric lobby feel more comfortable. Highly respected charities such as Tymes Trust refuse to adopt it and state that to change the name of a disease that already has neurological classification to one that has nothing simply in order to temporarily please certain doctors is exactly the same thinking that led to the WHO Collaborating Centre Kings College action over the dual classification of CFS.
- It is still the case that no full and frank disclosure or the provision of the required information to MEA members both extant/potential and the wider ME/CFS community has been given in order for the patient community to make an informed decision as to whether to support this charity or not.
- The Charity Commission of England and Wales states that it is mandatory for any charity to conduct itself with transparency and accountability. In the case of the MEA, nothing has changed. It still conducts itself with utmost secrecy and attempts to do deals in private behind the scenes such as the collusion by Dr. Shepherd with AfME as has been illustrated by the previous MEA Chairman in his statement.

Dr. Shepherd must now answer these most legitimate of questions in full raised by MEA members and the wider ME/CFS community with no further prevarications.

Jane Bryant

THE ONE CLICK GROUP

<http://health.groups.yahoo.com/group/THEONECLICKPROTEST/>