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THE AFME DOSSIER
A DOSSIER OF CONCERNS ABOUT THE CHARITY
ACTION for ME (AfME)

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January 2004

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The Countess of Mar, House of Lords, will be taking these matters further with the appropriate authorities.

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A DOSSIER OF CONCERNS ABOUT THE CHARITY

ACTION for ME (AfME)

ACTION FOR ME : 'FREE FROM BIAS'?

*"We define **accountability** and **transparency** as the provision of relevant and reliable information to stakeholders in a manner that is **free from bias**, comparable, understandable and focused on stakeholders' legitimate **needs** and will be assessing the Reports and Accounts on this basis."*

Statement from the Charity Commission of England and Wales

"The largest patients' charity, Action for ME, is working closely with Wessely and his colleagues on new research initiatives funded by the MRC and the NHS."

Statement from Lord Turnbull, House of Lords Debate, 22 January 2004

(Lord Turnbull is currently a member of the [Gibson ME/CFS Inquiry](#) and personally invited to be such by Dr Ian Gibson MP.)

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INTRODUCTION

ACTION FOR ME (hereinafter referred to as AfME) is a UK based charity. Questions about the charity's conduct and stance, repeatedly posed by both members/subscribers to both AfME and to the Charity Commission of England and Wales have remained unanswered.

AfME, constituted as a charitable company, has not seen fit to hold an Annual General Meeting (AGM) for its members/subscribers for the last TEN years - since 1996.

On the 9th November 2003, an AfME Trustee, Mr. T. Golding, stated in public and on the record at a London UK Local ME Group Meeting that the ME/CFS community (sufferers, carers and supporters), would be given answers to certain questions.

What are these questions? Members/subscribers need information regarding the following:

1. What is AfME's stance on current Government policy on the issue of ME/CFS?
2. By what mandate does AfME speak for its members/subscribers and the ME/CFS Community in support of its stance?
3. What is AfME's financial situation and from whom does it receive funding?
4. On what evidence does AfME sanction the promotion of management approaches that include psychosocial interventions such as Adaptive Pacing Therapy (APT) / Cognitive Behaviour Therapy (CBT) /Graded Exercise Therapy (GET)?
5. Who was instrumental in the present liaison of AfME with Government Departments and with the National Health Service?
6. How much money has AfME received as a result of that liaison?
7. What is AfME's structure since the alleged merger with Westcare (claimed to have taken place in September 2002)?
8. Is AfME accountable to its members/subscribers?

AfME members/subscribers have been denied an open dialogue opportunity with this charity for the last TEN years, yet engaging in dialogue with "transparency" is mandatory in accordance with the requirements of the Charity Commission.

Suitably full and frank answers to the legitimate questions set out in this document would provide some idea of the charity's present stance.

The concerns of the ME/CFS Community around AfME's conduct are presented below:

THE AFME STANCE

- AfME presents itself as the only major national ME/CFS charity in the UK that acts as spokesperson for adult ME/CFS sufferers. It presents itself in this way to the Government, to the Department of Health, to the Local Education Authorities and to the media. AfME is supposedly a patient focused organisation.
- Currently, the management regimes that AfME is sanctioning are psychosocial interventions promoted by a small group of psychiatrists led by Professor Simon Wessely. AfME is also **selling** these management

approaches direct to its members/subscribers through its so-called 'merger' with Westcare.

- AfME is receiving government money regarding trials of further psychosocial interventions, which have been recommended by the Medical Research Council in conjunction with Professor Wessely. These are the management regimes that have been consistently shown in major surveys to make many people worse.
- AfME itself carried out a survey of 2,338 respondents and in March 2001 published its report "Severely Neglected - M.E in the UK". (AfME promoted 'Severely Neglected' as the largest ME study ever done, for which it was reported to the Charity Commission). Of significance is the fact that in AfME's preliminary confidential version of that report dated 26th February 2001, it clearly states on page 6 that "graded exercise was reported to be the treatment that had made most people worse". This was entirely omitted from the final version of the report, and it is now the case that, in defiance of its own evidence but in conjunction with the current psychosocial model of ME that is being so heavily promoted by psychiatrists of the Wessely School, AfME is now actively promoting this very management strategy for those with ME/CFS.
- It is a matter of concern that AfME continues to support psychosocial interventions such as graded exercise, given the high drop out rates of any studies undertaken and the fact that graded exercise has left many so terribly disabled.
- The confidential report (never released) was unequivocal that rest, pacing of energy levels, dietary changes and nutritional supplementation were without doubt the most beneficial management interventions, yet these results were also omitted from the final report.
- This is despite the fact that serious concerns have been raised and sustained, since 1988, within the international ME/CFS patient community and the international ME/CFS research and clinical community, that the position taken by Wessely and his colleagues has caused and continues to cause damage to ME/CFS sufferers in the UK.
- On 22nd January 2004 it was stated in the House of Lords by Lord Turnberg that AfME is working closely with Professor Simon Wessely and his colleagues in the psychiatric lobby. As Professor Sir Leslie Turnberg, it was under his auspices as President of The Royal College of Physicians that the biased and much-criticised Joint Royal Colleges' Report on CFS was produced in 1996 that he fully supported. It is Lord Turnberg who is recorded in Hansard (HL4254) as asking Her Majesty's Government "What is their position on cognitive behaviour therapy for chronic fatigue syndrome as recommended by Professor Simon Wessely and colleagues". During the debate on 22nd January 2004, the Health Minister (Lord Warner), alluded to the fact that Professor Wessely had received a research medal specifically for his work on CFS/ME, (not, Lord Warner was at pains to point out, from the Royal College of Psychiatrists but from the Royal College of Physicians). What Lord Warner failed to mention was that the medal was awarded whilst Lord Turnberg was President of The Royal College of Physicians.
- It should be noted that AfME now seems to make no distinction between chronic "fatigue" and the "chronic fatigue syndrome" (another term for ME), even though there is extensive evidence that the two disorders are biologically different. It is the case that at one time, AfME even included within its logo the

words “Action for ME **and chronic fatigue**” (which it has now removed), and the Charity Commission has confirmed that AfME had made no representations to them concerning any amendment to its object statement which was granted in 1994.

- AfME has neither remit nor mandate to sanction or to promote anything that has been shown to make ME/CFS sufferers worse. It has not held an AGM that involved its members/subscribers for the last ten years, since 1996.

Even so, AfME maintains that it represents its members/subscribers and therefore the ME/CFS community at local, regional and national government and to the Health Service.

- Many frightened and very sick people are deeply dismayed that AfME purports to be the only viable support organisation that represents their best interests, when such is clearly no longer the case.

AFME MEMBERS/SUBSCRIBERS

AfME members/subscribers have not been privy to policy decisions made by this charity.

AfME is constituted as a charity company - a company founded for charitable purposes - that has Members and a Memoranda and Articles of Association.

AfME has a Constitution. Under this Constitution, members/subscribers are entitled to elect the Board of Trustees, the Chairperson and other Officers of the Board.

Not only have AfME members/subscribers not elected these Trustees, many of them do not even know who these people are.

As members/subscribers, do they not have rights?

They have the right - amongst others - to make, set and rescind policy on any area of AfME's operation.

In fact, AfME denies that it has a membership as such. It does not consider that the people who subscribe to the company by subscription are members but claims they are merely passive donators to the work of AfME. AfME uses the term subscribers but refuses to comment on what that term legally means.

AfME has been awarded many Government grants that have been obtained on the basis of AfME performing certain tasks in specific ways. Personal subscriptions obtained from AfME members/subscribers account for only a proportion of its income.

AfME members/subscribers have not been consulted regarding the terms of these tasks and arrangements.

AfME has also failed to properly inform, involve and consult its members/subscribers on questions of policy, policy making and the strategic direction of AfME as well as the form and function of this charity.

This has led AfME to adopt a strategic position, stance and vision of the future direction of this charity that is not shared by its members/subscribers because it lacks the mandate required.

AfME members/subscribers have been completely disenfranchised.

THE AFME ACTIONS

The Department of Health UK has allocated £8.5m to help UK ME/CFS sufferers. Whilst this is welcome, concerns abound over the involvement of AfME with the disbursement of that money, which members/subscribers do not wish to be devoted to more psychiatric studies but to research into the organic basis of the disorder.

National Health Service Hospital Trusts in the UK have placed bids with the Department of Health for this money that has been provided in order to assist ME/CFS sufferers.

This money is to be used to establish Centres of ME/CFS expertise across the country, to set up the development of services and to improve clinical care.

However, it has now become clear that the main management regimes that such Centres will be offering are to be psychosocial interventions and that these programmes will be under the direction mostly of psychologists and psychiatrists, some of whom (such as Professor Elsa Guthrie in Manchester) are known to specialise in somatisation disorders. Since the AfME Dossier was written in 2004, these 'CFS/ME' Centres have now been [condemned](#) by patients right around the nation.]

It is of serious concern that The York Review of the best “evidence-based” management regimes relied upon by the Chief Medical Officer’s Working Group on CFS/ME commented that the very few existing studies were of poor quality and that they do not detail what happened to those who had to drop out.

These are the treatments that the national patient organisation - AfME - is sanctioning, promoting and selling direct to the public.

The AfME stance over its role in the £8.5m awarded to help ME/CFS sufferers and these ME/CFS Centres is becoming clear.

AFME AND THE DEPARTMENT OF HEALTH

In regard to this money and how it is to be spent, AfME has made two public announcements:

1. That an AfME employee has been seconded to the Department of Health Secretariat to act as an Observer on the Steering Committee that has reviewed and will continue to review bids for the ME/CFS Centres and treatments.
2. That this same AfME employee is specifically employed to help the ME/CFS community work with the local PCTs (Primary Care Trusts, Health Service) in the development of these bids and facilities.

These publicly stated roles are contradictory. Precisely what is the AfME role in this? Observer or Participant?

Why did AfME select an individual for this key role seconded to the Department of Health Secretariat who has had but a few short months experience of ME/CFS? How can someone with such a lack of in-depth knowledge of this most complicated of illnesses liaise for the ME/CFS community with the Department of Health?

When attempts were made to question said key AfME employee on the 9th November 2003 regarding the ME/CFS Centres bids issue, the posing of these questions was refused by an AfME Trustee, Mr. T. Golding, who is also Chairman of a Local ME Support Group.

This AfME employee was unable to furnish this Local ME Group with any details of the 80 medical expressions of interests for the £8.5m whatsoever.

Despite repeated requests, AfME refused to provide ME/CFS sufferers with **any** full and frank disclosure of these bids. It refused to provide the full information required to review these bids locally, regionally and nationally in order to come to an informed decision.

On the 23 January 2004 the Department of Health announced the ME/CFS Centres and the Clinical Disciplines that would run them, without any apparent consultation with the ME/CFS Community.

The complete lack of transparency regarding these bids for the £8.5m has been execrable.

THE FURTHER PSYCHOLOGISING OF ME

Professor Simon Wessely (psychiatrist) stated in public and on the record at the Eliot Slater Lecture that:

“There is also a phenomenon known as myalgic encephalomyelitis - or ME. I will argue that ME is simply a belief, the belief that one has an illness called ME.”

However, contrary to Professor Wessely’s beliefs, ME is not a belief system. It is an organic illness. This is recognised by the international ME/CFS research and clinical community. The large body of research evidence demonstrating this fact continues to grow.

Yet the AfME charity continues to work with Professor Simon Wessely and his colleagues, to the apparent exclusion of other specialists, despite the concerns about the damage to ME/CFS sufferers in the UK caused by the approach of the ‘Wessely School’.

Canada has recently produced pioneering clinical [Guidelines, Treatments and Protocols](#) drafted under the authority of the governmental “Health Canada” by an Expert Medical Consensus Panel (available on

The eleven international ME/CFS expert physicians who made up the Panel, have between them diagnosed and/or treated more than 20,000 ME/CFS patients. This represents the most substantial breakthrough on treatments for ME/CFS sufferers worldwide. It is treatments like these that the ME/CFS community would like our Department of Health to consider, not those treatments propounded by the ‘Wessely School’ who do not believe that ME/CFS exists as a physiological illness.

An important question that presents itself is this. Why has this AfME charity not commented on the development of the Canadian Guidelines, Treatments, Definitions and Protocols far and wide on behalf of the ME/CFS community? Is this not part of its role and its duty to its members/subscribers?

Instead, AfME works with Professor Simon Wessely and the psychiatric lobby in the UK in order to further psychologise the physical illness ME to the detriment of all sufferers.

If there is no aetiological research, the only treatments available will continue to be APT/CBT/GET. Is this the intention?

Furthermore, when Professor Malcolm Hooper, Emeritus Professor of Medicinal Chemistry, who describes the horrors done to seriously ill sufferers of the neurological disorder ME (Myalgic Encephalomyelitis) published his recent paper entitled “The Mental Health Movement : Persecution of Patients”, Mr. Clark, the then CEO of AfME, actually denigrated this paper in public, in contrast to the ME/CFS

community, both national and international, which greeted Professor Hooper's paper with considerable gratitude and acclaim.

THE NON-EXISTENT AFME / WESTCARE MERGER

In September 2002, AfME announced that it had 'merged' with Westcare. AfME issued press releases on this so-called 'merger'. This information was put up on the AfME website, covered in its magazine and distributed to the media.

As late as November 2003, the Charity Commission of England and Wales had no knowledge that any merger between AfME and Westcare had taken place. In fact, the Charity Commission denied any merger existed and issued the following statement.

From the Charity Commission, 26 November 2003:

"We are not currently in correspondence with the charities [AfME and Westcare] about this issue [the merger]. We have previously considered this issue and provided advice on the basis of the information provided at that time. We are not aware that the trustees have decided to take forward the proposal and both charities remain on the Register. We have not been contacted with any current proposals for a merger and therefore cannot comment on these."

This runs utterly contrary to the copious AfME public statements on this issue that have been in the public domain since September 2002.

Just a few weeks ago, the Charity Commission was under the impression and publicly stated that AfME and Westcare were still operating as individual charities and no merger had taken place whatsoever.

On the 15 January 2004, a journalist questioned the Charity Commission again:

"Have the charities merged?"

The Commission answered: "The Commission understands that in September 2002 Westcare transferred all the charity's assets to Action for ME, in pursuance of the power of application contained in the charity's Trust Deed. In so doing, Westcare ceased to operate, and has recently supplied the Commission with the documentation necessary to remove the charity from the Register of Charities. In applying its funds by way of a transfer to Action for ME, Westcare has ensured these funds continue to be applied for the relief of persons suffering from ME and associated illnesses. This process has not resulted in the creation of a separate organisation: one charity has ceased to operate, and one charity has continued unchanged."

If AfME has spun its members/subscribers (as well as the public and the Charity Commission) a line over the non-existent 'merger', does this culture of spin pervade everything it does?

To summarise:

1. In September 2002, AfME announced that it had merged with Westcare.
2. In November 2003, the Charity Commission stated that it had no knowledge of any such merger having taken place and that both AfME and Westcare were still operating as independent entities according to its records and files.
3. Then in January 2004, sixteen months after the apparent merger, the Charity Commission stated that it had been given to understand that a transfer of assets had taken place and that Westcare no longer operates as a separate entity and that an application to remove Westcare from its books was in progress.

Members/subscribers of AfME should have been consulted regarding pursuance of a 'merger' between AfME, a Charitable Company and Westcare, a Charitable Trust. The form and function of these two entities is entirely different. Members/subscribers of AfME were not consulted.

This so called 'merger' changes the entire direction of AfME. This 'merger' has made AfME a direct provider of services to ME/CFS sufferers.

AfME is now selling such treatments as CBT/GET to the general public at considerable expense. Treatments that have not only shown themselves to be less than efficacious for sufferers, but in many cases have caused considerable damage.

THE QUESTIONS

Questions have been raised regarding AfME's financial probity because the form, function, strategic direction and workings of AfME are entirely unclear.

Members/subscribers of AfME have been unable to enter into free and frank dialogue with this charity since 1996. There are a substantial number of important questions that need to be answered by this charity:

1. Has AfME ever used funds on purposes for which they were not donated?
2. Why has AfME not held an AGM that involved its members/subscribers since 1996 - ten years?
3. By what mandate and remit does AfME represent its members/subscribers to Government and the Health Service given that it has not had an AGM since 1996?
4. What specific grants has AfME been given by Government? What tasks has AfME agreed to perform regarding these grants? List grants, define responsibilities and action.
5. Why does AfME work closely with Professor Wessely and his colleagues and the psychiatric lobby when this is clearly contrary to the wishes of the ME/CFS community, and doubtless of most AfME members/subscribers? Has AfME ever canvassed the opinions of its members on the approach of the 'Wessely School'?
6. Precisely what relationship does AfME have with Wessely/Chalder et al and the psychiatric lobby? Define.
7. Did conversations between the CEO of AfME and Wessely/Chalder et al take place at the weekend prior to the publication of the article dated 20 September 2003 published by the British Medical Journal entitled "Epidemiology of chronic fatigue syndrome and self reported myalgic encephalomyelitis in 5-15 year olds: cross sectional study" written by Chalder/Wessely et al or not?
8. Why has AfME failed to respond to the Wessely article in The Scotsman dated 5 January 2004?
9. Precisely what is the AfME role in its dealings with the Department of Health regarding the bids for the £8.5m? Define.
10. Why did AfME refuse to list the eighty medical expressions of interests regarding the £8.5m for view by its members/subscribers and for the ME/CFS community?
11. Why did AfME not give full and frank disclosure of these bids to Local ME/CFS Groups?

12. Does AfME subscribe to the fact that important subsets of CFS are the neurological/physical illness(es) ME and PVFS as defined by Ramsay and classified by the World Health Organisation (ICD-10. G.93.3) that is used by the rest of the world?
13. By what mandate does AfME speak for its members/subscribers and the UK ME/CFS community regarding its stance on the treatments psychosocial management regimes it is currently recommending?
14. Precisely what is AfME's financial involvement in the PACE/FINE trials? Define the AfME 'expenses' in regard to these trials and what it is proposed that these will consist of?
15. Why has AfME not commented on the Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols produced under the authority of the governmental "Health Canada" by an Expert Medical Consensus Panel? The eleven international ME/CFS expert physicians who made up the Panel, who have between them diagnosed and/or treated more than 20,000 ME/CFS patients? This represents the most substantial breakthrough on treatments for ME/CFS sufferers worldwide.
16. What is the difference between the terms members/subscribers that AfME uses? Please explain and legally define.
17. How are the AfME Trustees elected?
18. Please define the AfME categories of membership/subscription e.g. corporate, group, individual and so on. Please list numbers in each category thus enabling members/subscribers to see precisely how many members/subscribers AfME has.
19. List names of AfME Trustees/Affiliates/Officers who also run Local ME Groups.
20. Does AfME formally speak for Local ME Groups in any way? And if so, by what means?
21. Precisely what affiliation does AfME have with Local ME Groups? How is this conducted on a constitutional and managerial basis? How is this relationship regulated and maintained?

WHAT IS REQUIRED

1. AfME members/subscribers require and are entitled to a fundamental review of this charity's strategic direction and any other medium or long term organisational plans.
2. AfME members/subscribers require and are entitled to a fundamental review of AfME's policy portfolio in its entirety together with AfME's stance on policy issues.
3. AfME members/subscribers require a review of AfME's strategic direction and any other medium or long term organisational plans.
4. AfME members require that AfME commits itself as a matter of principle to fully informing and involving members/subscribers through the process of Consultation with members/subscribers before making any significant

organisational change or the creation and adoption of policy and about policy making in general. The results of the said consultation to be binding upon AfME.

CONCLUSION

AfME must be required to answer the serious concerns and questions raised in this document. Members/subscribers have not been given the opportunity to consult with this charity since 1996. Without doubt, many members/subscribers of AfME and people within the ME/CFS community will have other questions. For those who would like to pose further questions to AfME, please write to me at

mail@theoneclickgroup.co.uk

STATEMENT FROM THE CHARITY COMMISSION OF ENGLAND AND WALES

Transparency and Accountability

*“Transparency and accountability are important issues for the Charity Commission. The Charity Commission’s aim is to provide the best possible regulation of charities in England and Wales in order to increase charities’ effectiveness and public confidence and trust. That confidence rests in part on the assurance that charities are open and honest in explaining how they apply charitable funds. Charities have a statutory duty to provide the Charity Commission with a copy of its Annual Report and Accounts. We are currently running a compliance campaign to assess the extent to which charities are fulfilling that statutory duty. The focus of this report is on the accessibility of the information contained in charities’ Reports and Accounts. We will be running an analysis of 200 accounts from large charities (income >£10 million) in order to assess how comprehensive and accessible the information they provide is. We define **accountability** and **transparency** as the provision of relevant and reliable information to stakeholders in a manner that is **free from bias**, comparable, understandable and focused on stakeholders’ **legitimate needs** and will be assessing the Reports and Accounts on this basis.”*

- ends -

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Please note that this document has been produced after extensive consultations with the Charity Commission of England and Wales and with the invaluable assistance of the ME/CFS community. Thank you.

January 2004

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