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3<sup>rd</sup> November 2016

Dear Lord Hall

Formal Complaint to the BBC re: the purveying of mis-information on 1<sup>st</sup> November 2016

This is brought to your personal attention because it is such a serious matter.

The BBC is required to be accurate and impartial, but James Gallagher (the BBC News website Health and Science reporter who was responsible for the item that made the BBC headlines from 5.30am on 1<sup>st</sup> November 2016) was neither accurate nor impartial.

On BBC News 24 the breaking news ticker headline repeatedly announced across the screen: "A successful treatment for children with CFS is being trialled by the NHS."

The BBC's Charter says that its primary function is to inform, educate and entertain, but the BBC breached its own Charter by its 24-hour non-stop promotion of a study of myalgic encephalomyelitis/chronic fatigue syndrome in children and adolescents (the £1 million FITNET trial, which stands for Fatigue In Teenagers on the interNET) and which claims success for a behavioural modification intervention when there is no objective evidence of any such success in either children, adolescents or adults. Moreover, the study had not even started to recruit participants: this was not made clear and it was heralded as "Landmark chronic fatigue trial could cure two-thirds" but that was later changed to the nonsensical "Landmark chronic fatigue trial could treat two-thirds". Chronic fatigue is not the same as ME/CFS.

The item was described <u>thus</u>: "the BBC and their scientifically illiterate journalists imaginatively and dishonestly spun this as a 2/3 cure rate".

## **Specific aspects of the complaint**

- Professor Esther Crawley is currently under investigation by the GMC for negligent management of a young person with the condition in which she alleges to be an expert, this management being exactly the same as that which is to be used in her FITNET study so strongly promoted by the BBC. Had the BBC's journalist done his homework, it would surely have tempered his overly enthusiastic support for Professor Crawley.
- 2. Throughout the day, the BBC reporters did not place the issue in proper context: there was no mention of the discredited PACE trial of CBT/GET in adults: in 2011, it was hailed by the Science Media Centre and hence the UK media as successful, but following a five-year quest to obtain the raw data for re-analysis by independent statisticians, when the Judge ordered the raw data to be released, it was found to be fraudulent and that instead of the claimed recovery figure of 22% after CBT and GET, the actual figures were only 7% for CBT and 4% for GET, meaning that there was a null result from the PACE trial.
- 3. The reporting was inaccurate (66% of participants were said to be "cured") because it grossly exaggerated and mis-represented the findings of a small Dutch study in young people upon which the FITNET trial relies as evidence of efficacy: whilst there was a significant difference in school attendance at six months in those who received internet CBT versus those who received "usual care" (75% vs 16%), the ultimate findings of the Dutch study showed no difference between the groups at 2-year follow-up. The BBC reporter failed in his duty to mention the actual results of the Dutch study, which was that children who did not get any CBT did as well as those who did get CBT, nor did he mention that three of the four thresholds used in the Dutch trial for "recovery" were virtually the same as for the entry criteria into the trial, nor that two of the Principal Investigators of the PACE trial (Professors White and Chalder) commented that in the Dutch study, most children met the trial criteria for "recovery" when they entered the trial -- a comment not without irony, as exactly the same situation occurred in their own PACE trial of CBT/GET in adults.
- 4. Undue credence was given to the behavioural theory of ME/CFS even though that theory has long since been debunked throughout the international medical community.
- 5. The interview with Professor Crawley at 8.15 am on the BBC Today programme was heavily biased towards her own views, with very little time

given to the opposing views of Jane Colby, Executive Director of TYMES Trust (The Young ME Sufferers Trust, the longest established national UK service for children and young people with ME and their families and winner of the Queen's Award for Voluntary Service), so the BBC clearly did not present a balanced view.

- 6. There was a further lack of balance in that no medical expert who disagreed with Professor Crawley was interviewed even the Medical Advisor to the ME Association was not informed that this item was to be broadcast and was excluded from participation.
- 7. Based on the extensive biomedical evidence, the FITNET trial cannot offer hope or promise of recovery and to broadcast that it can is in breach of numerous medical codes of conduct and to mislead patients by promising a cure when there is no such certainty is in breach of the General Medical Council Regulations as set out in "Good Medical Practice" (2006):

"Providing and publishing information about your services – paragraphs 60-

60. If you publish information about your medical services, you must make sure the information is

factual and verifiable

61. You must not make unjustifiable claims about the quality or outcomes of your services in any

information you provide to patients. **It must not offer guarantees of cures**".

Although this is an issue for the GMC and not primarily for the BBC, nonetheless the BBC gave undue prominence to unproven interventions and incorrectly reported the trial as curative.

- 8. Given the insistence of the psychosocial school that ME/CFS is a behavioural disorder, this FITNET trial is likely to become another weapon to force children with ME/CFS to undergo interventions which can make them even more sick and its extensive roll-out throughout the NHS may be used as a vehicle for the forcible removal of children from their parents and home, a situation that is already rampant in the UK.
- 9. The BBC coverage was so hyperbolic and it afforded the FITNET trial so much publicity that it was clearly organised as a counter-punch to the anti-PACE evidence which is now gaining world-wide attention.
- 10. Many international medical scientists and clinicians with whom I am in contact who are involved with the biomedical pathology of ME/CFS (including not only those in the UK but those in Canada, the US, Scandinavia, Holland,

Australia and New Zealand) are appalled at such unjustified and uncritical publicity afforded by the BBC to a study which is based upon speculation, not upon science.

For the avoidance of doubt, I have provided background information.

## **Background to the complaint**

It seems that the BBC relies on briefings provided by the Science Media Centre (SMC) without bothering to verify the facts. Such lazy reporting is unacceptable because it is misleading and is harmful to the public. The Science Media Centre began work in 2002 to operate like a newsroom for national and local media when science stories hit the headlines. It is funded by, amongst others, the pharmaceutical and chemical industries. The SMC's covert purpose is to ensure that journalists and the media report scientific and medical matters only in a way that conforms to Government and industry's "policy" on the issues in question. To that end, the SMC provides "training days" for journalists so that what they report on scientific and medical issues is effectively influenced and controlled by the SMC. Its founder member is psychiatrist Professor Sir Simon Wessely, whose life's work consists of asserting that ME/CFS is not an organic but a behavioural disorder that can be cured by "cognitive restructuring" and graded aerobic exercise (ie. the interventions to be used in the FITNET study).

The BBC's science editor David Shukman's unqualified support for the SMC is a matter of national concern because it is to the serious detriment of very sick people: for many years the SMC has campaigned tirelessly against people with ME/CFS and is internationally discredited because of its well-documented and indisputable bias (The Role of the Science Media Centre and the Insurance Industry in ME/CFS: the facts behind the fiction: Professor Malcolm Hooper, September 2013).

Not for the first time, the BBC has reported as fact what was an outright untruth about ME/CFS, for example, its Science Correspondent Tom Feilden's overly excited introduction to his interview with Professor Wessely about ME/CFS on the BBC's Today programme on 29<sup>th</sup> July 2011 exemplified a failure to exercise the requisite journalistic neutrality when reporting a "story". Feilden won the UK Press Gazette's first ever specialist science writing award for breaking the story the SMC gave him about the alleged harassment and intimidation of researchers working on CFS/ME. The SMC had nominated him for the award, but Feilden's "story" of threats and harassment from ME/CFS activists was found to have been orchestrated and promoted by the SMC and in October 2016 was dismissed by the Judge at the First Tier Tribunal as "without foundation" and "wild speculations".

It is disquieting that James Gallagher is in fact a member of the SMC's Advisory Panel (<a href="http://www.sciencemediacentre.org/about-us/governance/">http://www.sciencemediacentre.org/about-us/governance/</a>), so he had an undeclared conflict of interest.

He was clearly promoting the SMC's agenda and his story was nothing more than an unwarranted advertising campaign for Professor Esther Crawley's FITNET study of behavioural interventions in children and adolescents with ME/CFS.

It is not surprising that the "experts" put forward by the SMC to support the news item were Professor Esther Crawley herself, her close friend Professor Stephen Holgate, and Professor Paul McCrone (who was involved with the now-discredited PACE trial of CBT/GET in adults), all of whom are known to be biased in favour of the SMC's agenda. Professor Holgate referred to Professor Crawley's FITNET trial as "high quality research", but one senior UK Consultant Physician who specialises in the multi-systemic pathology of ME/CFS asks how a study that is carried out on Skype and which does not even meet the patients face-to-face, let alone examine them over time, can be described as "high quality research".

The FITNET trial was due to have started in May 2016, but it seems that it could not secure enough volunteers, so a media-hype was necessary; as customary with the SMC's tactics, this was orchestrated to overshadow the evidence of serious biomedical pathology presented at the International Association for CFS/ME conference in Fort Lauderdale held at the end of October 2016 (evidence which the SMC chose to ignore) <a href="https://listserv.nodak.edu/cgi-bin/wa.exe?A2=ind1611a&L=co-cure&F=&S=&P=9740">https://listserv.nodak.edu/cgi-bin/wa.exe?A2=ind1611a&L=co-cure&F=&S=&P=9740</a>.

I ask that you ensure that the BBC issues a prominent retraction of its endorsement of and support for the FITNET study and, to counter-balance its support for behavioural interventions for a proven and classified neuroimmune disorder, the BBC offers a commensurate right of reply to those with an understanding of the biomedical nature of the disease.

The Countess of Mar