

NEUROIMMUNE  
*alliance*



The Leveson Inquiry  
Royal Courts of Justice,  
Strand,  
London  
WC2A 2LL

8<sup>th</sup> February 2012

Dear Lord Justice Leveson

I write with regards to the media's code of conduct in respect of recent articles published by The Sun and The Telegraph and whether or not disability discrimination comes under the Leveson Enquiry remit.

The Media have a moral and social responsibility to tell the truth but you and I both know how journalists gain information and report it can stray far from any issued guideline.

Over the past year there has been a rise in the number of articles published on Myalgic Encephalomyelitis, or M.E, all fed through the Science and Media Centre who are giving a grossly unbalanced view on the disease and I feel that journalists have no right in portraying severely ill patients as anything other than severely ill.

I understand you called Fiona Fox to testify on January 24<sup>th</sup>. The Science and Media Centre are at the heart of the media controversy over M.E/CFS and I believe that Ms Fox has not told you the full story. Fox stated "At the SMC we think it is healthy for opinionated columnists to challenge science and scientists in vigorous terms but we feel that they should not be free from the general expectations of truth telling and accuracy that govern the rest of journalism."

There is a coerced smear campaign designed specifically to abuse and ridicule M.E patients and I call on you to make this public in your enquiry and impose rules stating that journalists cannot form opinions on medical conditions nor print inaccurate facts.

Such media manipulation is inevitably linked to the suppression of justified concern from a disempowered population, as has been shown to be the case – at least two broadsheet Health Editors have confirmed that it is not editorial policy to report biomedical findings in ME/CFS and that they will use only information on "CFS/ME" that they get from the SMC. Given the fact that Wessely is a member of the SMC's Scientific Advisory Panel, such confirmation is unsurprising.<sup>1</sup>

<sup>1</sup> [www.meactionuk.org.uk/Defiance\\_of\\_Science.htm](http://www.meactionuk.org.uk/Defiance_of_Science.htm)

In August 2011 there was a slur of articles printed in The Times, [redacted] The Observer, The Guardian [redacted]

<http://www.timeshighereducation.co.uk/story.asp?sectioncode=26&storycode=417219&c=1>  
<http://www.guardian.co.uk/society/2011/aug/21/chronic-fatigue-syndrome-myalgic-encephalomyelitis>  
<http://www.spectator.co.uk/essays/all/7190703/mind-the-gap.html>

Since the Lombardi et al findings of the third human retrovirus in the blood of M.E patients were published in the journal Science in October 2009, my organisation Neuroimmune Alliance, has been in regular contact with specific health writers and editors ensuring they get the best possible sources of information for any M.E related story.

Editorial and journalistic bias may not be issue as critical as the invasion of privacy via phone hacking, but it IS an issue of patient safety and protecting those who are most vulnerable.

The par of course for being a good journalist is to write unbiased articles based on the medium of fact. Of course opinion is going to be part of any authors work and opinions, due to human nature, bring with them the ability to agree or disagree with those views expressed.

However on occasions journalism can turn sour and articles by Robin McKie, [redacted] and Rod Liddle are sadly such occasions which I believe violate the Editors Code of Practice, Point 1, whereby The Press must take care not to publish inaccurate, misleading or distorted information.

Faced with an idea that these journalists do not agree with or are told not to report, i.e. that M.E is a neurological disease, such comments were made, such as [redacted] or assuming M.E patients are "fraudulently claiming benefits"(Rod Liddle). These are entirely untrue statements with no basis of fact whatsoever.

"Many claim that their condition is the result of a viral infection or exposure to environmental toxins. Research to date has failed to support conclusively this hypothesis..." again an untrue statement.

Epstein Barr virus(EBV) causally involved in 81% of 106 consecutive Chronic Fatigue Syndrome(CFS) cases

Diagnostic serologic panel available for physicians treating CFS patients; diffuse and restricted component of EBV Early Antigen indicate abortive non-permissive incomplete virus replication CFS is the result of a non-permissive herpesvirus infection; one or more of EBV, HCMV and/or HHV6 Use of long term antiviral treatments improve Energy Index Point Score, key measurement tool for EBV CFS diagnosis and recovery, with sustained significant improvements to quality of life for patients.

"An update on the management of glandular fever (infectious mononucleosis) and its sequelae caused by Epstein-Barr virus (HHV-4): new and emerging treatment strategies" by Dr. A. Martin Lerner was published today by the journal Virus Adaptation and Treatment. Following the successful May release of Dr. Lerner's "Subset-directed Antiviral Treatment of 142 Herpesvirus Patients with Chronic Fatigue Syndrome" in Virus Adaptation and Treatment, the journal now publishes a deeper look at the "common thread" virus causing CFS...EBV.

"It wasn't until psychiatrists such as Prof Wessely started treating the condition psychologically that real progress was made." Again, where is the basis in fact here, this is an opinion of a journalist who has had links with the Institute of Psychiatry where Professor Wessely works, and can therefore be considered a statement of bias. If progress had been made in M.E, why has someone died of the disease as recent as last month? And what about the case of a twenty year old girl who took her own life due to being placed in psychiatric care, somewhere where nobody with a neurological disease should be.

Robin McKie in the Observer on Sunday 21<sup>st</sup> August stated, "According to the police, the militants are now considered to be as dangerous and uncompromising as animal rights extremists." Where is the evidence of these so called threats? And how, please, can you tell me the people who are so terribly ill

in agonising pain with the inability to move, eat or do anything other than lay in a dark room can be dangerous?

The media has veered into political territory of late concerning the illness Myalgic encephalomyelitis and its tone has become aggressive, accusing patients of being 'extremists' and "militants".

For better or worse, the press release that the majority of these articles were based upon was clearly drafted by none other than Professor Wessely through the Science and Media Centre? How else would the same article become regurgitated over a period of a month?

The fact that the press only ever reports one view and one view only of M.E, those of Professor Wessely and his colleagues is evidence that the editorial line is not dictated from within, but by Professor Wessely himself.

Naturally, journalists opinions are formed from cultural biases derived from their education, the books read, the lectures attended, the media watched and so on. But why does this give them the right to only print one view of M.E. Not one article in the mainstream press concerning biomedical research has been published since October 2009. The Invest in M.E Conference 2010 went unreported and I assume the 2011 Conference will also go unreported, the replication of the Lombardi et al findings by Alter/Lo in August 2010 went unreported yet Wessely's colleague, Professor Peter White had a number of column inches devoted to his PACE trial results – again all assuming the same viewpoint.

The mainstream media in this sense are not allowing their readers to gather the bigger picture, and let them deal with their own opinions and allow the reader to consider facts and arguments that they might not otherwise be made aware of. Surely this is the role and responsibility our press need to take?

Patients concerns over editorial bias within the media with regards to M.E stories are not a new issue. All mainstream media articles on M.E/CFS over the past two years have specific quotes from either Professor Wessely or his colleagues at the Institute of Psychiatry – which either degrade or vilify patients or promote their skewed psychosocial school of thought. In an article in last year's Guardian by Sarah Boseley entitled "the trouble with M.E" one of Wessely's colleagues, Dr Alastair Santhouse was quoted saying he was deeply concerned by much of the press coverage, which depicted ME/CFS as a terminal illness and wrote to say so in the British Medical Journal.

It is time that the Press Complaints Commission looked into how the media is effectively being controlled by Professor Wessely through the Science and Media Centre, making the actions of a few individuals a slur on the community as a whole.

Let's take a step back, let's say there was evidence of hate mail being sent. Myra McClure quoted this in The Guardian.

*"I published a study which these extremists did not like and was subjected to a staggering volley of horrible abuse," said Professor Myra McClure, head of infectious diseases at Imperial College London. "One man wrote he was having pleasure imagining that he was watching me drown. He sent that every day for months."*

I have stated in correspondence with Professors Simon Wessely and Michael Sharpe that the ME community I represent and work with does not nor will never condone threatening behaviour.

On the flip side, without doubt I believe it is the responsibility of the media to understand *why* such threats exist and report ALL the facts, not just one opinion or set of opinions from ONE profession.

This week on 25<sup>th</sup> and 26<sup>th</sup> January more abuse written specifically to target M.E patients was published in The Sun and The Telegraph.

<http://politicalscrapbook.net/2012/01/rod-liddle-disabled-the-sun/>  
<http://www.meassociation.org.uk/?p=10126>

<http://blogs.telegraph.co.uk/news/jamesdelingpole/100132880/the-fake-disabled-are-crippling-our-economy/>

No disease is 'fashionable'. People do not choose to become unwell. The first registered outbreak of M.E was in 1955 at the Royal Free Hospital. Holmes devised the first M.E criteria in 1988. This is not a disease that is a curse of modern times, it is a disabling neurological condition that deserves to be treated with respect, not belittled and victimised by journalists such as Rod Liddle.

I am a sufferer of M.E and CEO of the charity Neuro-immune Alliance. I have not met an M.E patient that was claiming to be unwell when they were physically fine. All the patients I have met with have been terribly unwell, most of them housebound if not confined to their beds.

I myself suffer from immune deficiency caused by M.E, hepatitis and mitochondrial dysfunction. Mr Liddle implies that I 'enjoy' living this way so that I can claim benefits and not have to work, that I 'enjoy' being in pain 24 hours a day. I would much rather take the job I was offered in New York than have the 'luxury' of using a disabled toilet.

Paul Burstow from the Department of Health wrote on 12<sup>th</sup> September 2011 that he classed M.E as "a long-term neurological disease of unknown cause." Is this not good enough for Mr Liddle?

Dr Jose Montoya of Stanford University has found pathogens ranging from HHV6 to EB to Herpes Simplex to Coxiella burnetti to Mycoplasma pneumonia to Chlamydiae pneumonia. One interesting and quite ill subset with high PCR and low antibody levels of HHV-6 had HHV-6 integrated into their genomes. He noted one patient who had low antibody titers of all pathogens but with very high levels of PCR validated chromosomally integrated HHV6.

The Norwegian Directorate of Health has apologised for the way in which ME patients in Norway have been treated. This follows the publication of the ground-breaking research from Haukeland University in Bergen.

After the publication of the Rituximab study by Fluge et al <sup>2</sup> and extensive media coverage since then the Norwegian Directorate of Health gave a short statement on TV2 channel, see TV2 Nettavisen, a statement from the Norwegian Directorate of Health has been received where they apologised for not having provided the necessary and proper health services to persons with ME.

Such a public apology from a governmental health agency has never occurred before.

Bjørn Guldvog, Deputy Director General of the Norwegian Directorate of Health made the following statement:- "I think that we have not cared for people with ME to a great enough extent. I think it is correct to say that we have not established proper health care services for these people, and I regret that."

I believe the UK press should do the same.

Even articles that prove the severity of M.E trivialise the illness, for example, the headline Mother arrested as 'yuppie-flu' daughter is found dead after 16 years in bed.

Read more: <http://www.dailymail.co.uk/news/article-1092865/Devoted-mother-arrested-mercyc-killing-yuppie-flu-daughter-died-massive-morphine-overdose.html#ixzz1kgKz8D2g>.

<sup>2</sup> <http://www.plosone.org/article/info:doi%2F10.1371%2Fjournal.pone.0026358>

One journalist described Lynne Gilderdale, who died of M.E after an overdose in 2008, as "I've seen patients paralysed, dying Aids victims, starving children... but I've never seen anyone as ill as Lynn

Read more: <http://www.dailymail.co.uk/health/article-1093016/Ive-seen-patients-paralysed-dying-Aids-victims-starving-children-Ive-seen-ill-Lynn.html#ixzz1kgLEY2xT>

This misrepresentation by the media is the reason why nobody takes M.E seriously in the United Kingdom.

In 2003, an ME sufferer named Sophia Mirza was sectioned in Britain—police broke down the door and took her to a psychiatric hospital. Two years later, she died from complications of the disease. Though Mirza only spent 13 days in the hospital, her mother has gone on record saying that the ordeal had a devastating effect on her already fragile condition. She had actually been improving until that point.

In Kay Gilderdale's memoirs she described Lynne's treatment as having nurses push her out of bed and call her a "silly little girl".

In August a 12-year-old girl in Spain was taken by police to a local psychiatric ward. Although she's been diagnosed with severe ME by specialists, Social Services thought she should be attending school. They're forbidding the girl's mother (who also has ME) from seeing her.

Don't assume this kind of thing can't happen here.

#### **Death threats**

The majority of M.E sufferers I work with thankfully do not experience regular hospital visits but sadly there are the 25% who are too sick to be cared for at home and need specialist care which gravely means a trip to the psychiatric ward in the cases of most NHS hospitals where they are barred from biomedical treatment and only receive Graded Exercise Therapy or Cognitive Behaviour Therapy — which has been proven to make patients worse. Sadly the majority of funding over the past twenty years into M.E has been into psychological research — views promoted by the aforementioned psychiatrists who have absolute control over the patient whether it be how they are treated in hospital or what they read about themselves in the press. This monopoly has to end.

Given what happened to Sophia Mirza, the child in Spain has good reason to fear for her life.

On the flip side, not one psychiatrist has died at the hands of an ME patient.

Maybe the media is chasing the wrong story.

I leave this letter with some old photographs. Perhaps it will allow clarity and remind them the difference between extremism and disease.



After M.E

Before M.E

Sincerely

Gabrielle Lewis  
Neuroimmune Alliance