

The Murky Waters of an Invisible Illness

“The UK Medical Research Council is in possession of a secret file on Myalgic Encephalomyelitis (ME) that contains records and correspondence since at least 1988; the file is held in the UK Government Archive at Kew and cannot be opened until 2023. This present document is an overview of the misinformation and contradictions about Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) that have pervaded some UK Departments of State and other agencies since 1988. It also considers the involvement of certain UK psychiatrists who have proven vested interests in the propagation of this misinformation that is contrary to world-wide scientific evidence and that for two decades has resulted in the medical abuse of UK patients with ME/CFS.” (Hooper: Magical Medicine 2010)

The psychiatric lobby are risking the lives of these patients, yet Government policy dictates their beliefs. Our lives are really in their hands. This collective of psychiatrists, known as the ‘Wessely School’, has propagated untruths and falsehoods about ME to the medical, legal, insurance and media communities, as well as to Government Ministers and to Members of Parliament.

Influenced by the propaganda, Government bodies such as NICE, the Medical Research Council and the Department of Work and Pensions have continued the existence of the same falsehoods with the result that patients are left with no treatment. When treatment is offered it is often inappropriate with some adults and children being forced into psychiatric therapy at the Government’s expense or worse sectioned for their “abnormal illness beliefs”. Yet, the Government refuses to fund any *biomedical* research into the condition.

After innumerable communications with the previous Department of Health, they appeared happy to pass the buck to NICE, stating over and over that there is a “medical disagreement” over ME/CFS. The Government also state that they support the WHO ICD-10 Classification when clearly they do not; all treatment protocols are based around psychiatric treatment plans.

People in positions of power are misusing their power against sick people and are exploiting their positions to further their own vested interests, but no-one in authority is listening, at least not until they themselves or their own family join the ranks of the psychiatrically-persecuted, when they too come up against a wall of utter indifference.

The previous Government tried to bury their lies under the carpet. We hope Cameron’s new Coalition will not do the same.

ME and the Medical Profession

Many misinformed medical professionals believe that because the results from ME patients often come back normal there cannot be anything physically wrong with them. Dig deeper and you’ll discover this is not the truth.

In 2001 the US Centres for Disease Control pointed out that basic laboratory tests are insufficient for ME/CFS patients because it is known that routine screening is normal in 90% of such patients, thus highlighting the need for sub-grouping and for more complex investigations such as immunological assays, nuclear medicine screening and gene expression profiling.¹

Recently the CDC has reorganised their Chronic Viral Diseases Branch; their chief, Dr William Reeves, a well known sympathiser of the Wessely School, has been replaced with respected virologist Dr Elizabeth Unger.

In the UK, however, existing policy commands the non-investigation of ME/CFS patients other than by routine blood tests. It commands that no specialist testing or facilities other than psychiatric “fatigue centres” are needed for the care of ME/CFS patients; it commands that specialist training for doctors about the disease is neither necessary nor relevant; it commands the denial of appropriate medical care.

This is the approach advocated by the Royal Colleges Report: **“Perform the minimum number of investigations”** and **“Provide appropriate and unambiguous reassurance when there is no evidence of relevant physical pathology”** [which there isn’t going to be if you don’t run the tests!]².

Most shockingly, current policy approves the use of Court Orders for the compulsory removal from their home of both children and adults with ME, under the auspices of the Mental Health Act, if patients decline psychiatric intervention. The tragic story of Sophia Mirza is a case in point.³

Professor Simon Wessely himself has stated that ME is a waste of money and that sticking to his psychosomatic diagnosis and treatment is the only way forward.

*“Functional somatic syndromes (chronic fatigue syndrome, multiple chemical sensitivity, fibromyalgia, irritable bowel syndrome and tension headache) **are associated with unnecessary expenditure of medical resources.** If we accept that functional somatic syndromes are considered together, we open the way for more general strategies for their management”⁴*

When ME biomedical research and researchers have been starved of funding by the UK Medical Research Council it is particularly galling to hear that the charity AYME’s medical

¹ Co-Cure RES: NOT: 17th July 2001

² Essential skills/tasks for a multidisciplinary CFS unit Royal Colleges Report 1996

³ <http://www.sophiaandme.org>

⁴ (Functional Somatic Syndromes: one or many? Lancet 1999:354:936-939)

advisor, Esther Crawley, is to receive £160,000 from the Linbury Trust and the Ashden Trust to look at the psycho-therapy which is the Lightning process.⁵

It appears that the former Department of Health and NICE Executive Andrew Dillion remains unaware that American ME/CFS experts have concerns about Wessely's approach: Professor Charles Lapp from the Hunter-Hopkins Centre, Charlotte, North Carolina, is on record as saying: *"In my opinion, cognitive behavioural therapy is widely maligned because of the British approach, which presumes that (ME) CFS has no organic basis and is therefore contradictory to current science. (The UK) type of CBT assumes that somatic symptoms are perpetuated by errant illness beliefs and maladaptive coping"*.

Professor Nancy Klimas from the University of Miami is on record as saying: *"I don't take the British view that CBT is the one thing you can do to effectively treat (ME) CFS"*.

Dr David Bell from New York is on record as saying: *"I don't refer (ME/CFS patients) to outside CBT therapy"*.

Dr Daniel Peterson, ME research pioneer and former Medical Director of the Whittemore Peterson Neuro-Immune Institute, Nevada, is on record as saying: *"Sending patients to therapists who don't understand (ME) CFS isn't something I'd comfortably do"*. These quotations can be found in CFIDS Chronicle, spring 2006.

Here is hard evidence that the "treatments" offered by the £11 million Government-funded fatigue centres are psychiatrically-biased and that the clinics make no differentiation between those with ME/CFS and those with other chronic fatigue states....perfect setup for the Oxford Criteria. They don't believe we are truly sick....now, what did Mr Cameron say about "cutting out waste". How about starting with the NHS 'Fatigue' Clinics?

*"My own view has long been that the controversies about CFS are essentially those of a much larger, if less vocal, group of patients. That is the one-third of medical outpatients who have **conditions that are defined only in terms of symptoms without the presence of what we call disease**"⁶*

*"Whatever their biological basis, **there is strong evidence that symptoms and disability are shaped by psychological factors. Especially important are the patients' beliefs and fears about their symptoms.** Research in several functional syndromes has found that a strong belief and preoccupation that one has a "medical disease" and a helpless and passive*

⁵ [<http://www.bristol.ac.uk/ccah/news/2010/22.html#dresthercrawley>]

⁶ Michael Sharpe *The English Chief Medical Officer's Working Parties' report on the management of CFS/ME: Significant breakthrough or unsatisfactory compromise?* Journal of Psychosomatic Research 2002;52:6:437-438.

<http://www.ingentaconnect.com/conten...00005/art00012>

*attitude to coping is associated with persistent disability...Some persons appear to exaggerate symptoms but this is often hard to prove”.*⁷

One severely affected patient has described being put on gym machines, ending up in bed for several months. In a letter to the patient’s GP, psychiatrist Peter White from St Bartholomew’s Hospital, London, wrote that symptoms were the result of deconditioning, that fear and anxiety prevented the patient from exercising and that psychological factors contributed to the illness. It is reported that in the Greater Manchester area, a psychiatrist unknown to that area has come from nowhere and been made Head of the new “CFS/ME” service, with sufferers being told during cognitive behavioural therapy (CBT) sessions that they have a ‘fear of activity’ and ‘motivation problems’.

Their view is that ME patients are deconditioned, and that this is the cause of most of our symptoms. White, Wessely and Sharpe perpetuate that ME patients have a phobia of exercise and go out of their way to avoid even minor activity, hence they are encouraging their own cycle of disability. **This is why they advocate Graded Exercise.**

*“..In most cases of chronic fatigue, few laboratory investigations are necessary. All patients should have a psychiatric history taken and their mental state examined.... The psychiatric assessment should be systematic... It is our experience that delay in diagnosis resulting in long periods off work and referral to multiple 'specialists' should be avoided as they can entrench illness behaviour”*⁸

*“Abnormal physical signs should not be accepted as compatible with a diagnosis of CFS.”*⁹

*“The term ME... may mislead patients into believing they have a serious and specific pathological process affecting their muscles and brain.”*¹⁰

"Reports from specialist settings have shown statistically increased rates of abnormal results on tests for parameters such as antinuclear factor, immune complexes, cholesterol, immunoglobulin subsets, and so forth.... Their significance is for researchers rather than clinicians, and we feel that routine testing for such variables is more likely to result in

⁷ . Functional Symptoms and Syndromes: Recent Developments. Michael Sharpe, Trends in Disability 2002, UNUM. This report can be downloaded here <http://tinyurl.com/29f8wl>

⁸ Chronic fatigue syndrome and occupational health A Mountstephen and M Sharpe, Occup Med 1997;47:4:217-227 <http://occmed.oxfordjournals.org/cgi...tract/47/4/217>

⁹ Sharpe M, Chalder T, Wessley S Chronic Fatigue Syndrome: A Practical Guide to Assessment and Management, General Hospital Psychiatry 1997;19:3:185-199. <http://www.kcl.ac.uk/content/1/c6/01...Sharpe1997.pdf>

¹⁰ Joint Royal Colleges Report on CFS, October 1996, UK

iatrogenic harm than good. *There is currently no diagnostic test or pattern of tests that can assist in the diagnosis of CFS.”*¹¹

Our question to the new coalition, as a brand new Government what are you going to do about the corrupt situation within NICE and the Department of Health where psychiatrists are dictating Government policy?

Vince Cable stated back in 2009 to the Kingston and Richmond ME Group:

“The Liberal Democrats have long argued that funding and research must be focused on the ‘biomedical’ factors involved and not just simply managing the ‘psychological’ issues. Whilst I welcome the fact that NICE conducted an investigation into ME/CFS, I do understand and empathise with the concerns raised about the findings. The ineffectiveness of the Randomised Controlled Trials is just one weakness. In failing to recognise the biomedical problems of ME sufferers, the NICE guidelines also fail to recognise the needs of ME sufferers. To help address the unique challenges posed by a complex and poorly defined condition like ME, the Liberal Democrats believe in the establishment of an independent scientific committee to oversee all aspects of ME research. We would also like to see the government and the Medical Research Council work with ME sufferers and biomedical researchers in order to achieve a proper understanding of the condition, challenge unjust perceptions and consider the issue of research funding.”

We couldn't have put it better. But just how deep does Mr Clegg and Mr Cable think this runs?

The current guidelines for ME are based on evidence of CFS treatments recommended in 2002 by NHS Centre for Reviews and Dissemination at the University of York - a flawed study. It did not study up to date literature, its Graded Exercise trial had a dropout rate of 18% with 38% of patient experiencing a worsening of symptoms and it failed to distinguish between depressed patients, patients with Fibromyalgia and ME patients.

The findings of the York Review were passed to the Chief Medical Officer's Working Group headed by Psychiatrist Professor Michael Sharpe (Institute of Psychiatry) who stated of ME patients,

“Those who cannot be fitted into a scheme of objective bodily illness yet refuse to be placed into and accept the stigma of mental illness remain the undeserving sick of our society and health service”.

¹¹ Sharpe M, Chalder T, Wessley S et al, [Chronic Fatigue Syndrome: A Practical Guide to Assessment and Management](http://www.kcl.ac.uk/content/1/c6/01...Sharpe1997.pdf), General Hospital Psychiatry 1997;19:3:185-199
<http://www.kcl.ac.uk/content/1/c6/01...Sharpe1997.pdf>

The NICE Guidelines are recommended by steering groups who have TOO much affiliation with the Chronic Fatigue Research and Treatment Unit. This is jointly run by King's College Hospital and headed by Professor Wessely himself: this national specialist service undertakes assessment, treatment and research. General Hospital Psychiatry researchers are involved, for example, in the MRC PACE Trial, the largest trial of treatments for Chronic Fatigue Syndrome/ME to date, which is testing the effectiveness of different therapies. Does no one see this as wrong? Why does the Psychiatric profession hold sway over this illness when there is not ONE Government funded institution to research or treat the ME Patient? This is the same institute who carried out a purposely flawed XMRV study.

To highlight as an example how CFS Clinics are perpetuating these Psychiatrists' dangerous beliefs and what a waste of Government money these CFS Clinics are, we have included an example from the Liverpool CFS Clinic handout "**NO EVIDENCE OF DISEASE**" as a case study. To quote:

We now know from the medical research:

"There is no persistent virus, no muscle disease or damage"

"There is no hidden disease (p49)"

And *"Your thoughts about these symptoms are very important"*

If you: *"Fear the symptoms, misinterpret the symptoms as signs of disease or relapse, monitor the symptoms, feel frustration with the symptoms & limitations in lifestyle - this will cause further nervous system arousal with more symptoms that can perpetuate the condition."*

The booklet gets more hostile and forceful in manner as it goes on. It begins by sounding understanding; empathising with the patient, making observations about things that the patient can relate to; but as the leaflet goes on it stops the facade and reveals its true psychiatric intent.

For example, the leaflet refers to symptoms more as *"physical sensations"*. **This is wholly relevant as it highlights the fact that they believe we are not physically sick, but suffering from illogical thought processes, that our illness is idiopathic, psychosomatic,** therefore the patient does not have symptoms of a physical disease, just unpleasant feelings resulting from stress and lack of exercise.

The use of the phrase *“physical sensations”* is horribly reminiscent of: *“misinterpretation of associated bodily sensations”*¹²

“Chronic Fatigue Syndrome: What you need to know to get better

This booklet has been written with the help of patients who have made a full recovery from Chronic Fatigue Syndrome. Facts and information which were important to them in making this recovery have been included.

“All of the changes listed above can be reversed by a therapeutic activity programme” (p.14)

“Activity or exercise cannot harm you” (p. 50)

“The type of exercise needed for recovery is aerobic exercise” (p. 53)

“Athletes at the start of the season do not expect to achieve full potential in the first days or weeks of training.

They start building up fitness and stamina gradually, in a sustainable way over many weeks. They expect symptoms of deconditioning, seeing them as a sign of unfitness, not of physical disease.

They know as stamina and fitness increase muscle pain and fatigue will disappear.” (p. 51)

“First impressions of an activity plan

...The increase in symptoms is only temporary.

Those who persevere at this difficult point notice that over time as they become fitter, the symptoms of physical deconditioning gradually lift” (p. 51)

¹² Richard Mayou, and Michael Sharpe, Treating medically unexplained physical symptoms Effective interventions are available BMJ 1997;315:561-562)

"The key to successful recovery is:

If possible on a bad day try to do the same amount of exercise as the day before but no more.

It will be a struggle but you will not harm yourself" (p. 64)

"Those who have recovered experienced bad days with increased symptoms, but by working through their thoughts about those symptoms, using their understanding of physical deconditioning, they managed to overcome their symptoms and the fears." (p. 64)

"Restarting exercise after a cold or setback

...Symptoms may increase again causing fear of relapse, but remember these are the symptoms of physical deconditioning, nothing else." (p. 65)

"Summary of Activity Plan

...2. Choose an aerobic activity to do at least twice a day.

...5. On bad days if possible try to do what you did the day before. This is the key to a successful recovery.

....6. Your symptoms will increase at first but this is only temporary. (p.68)"

Therefore the Psychiatrists are perpetuating the dangerous view that there is no organic pathology of a viral or bacterial nature behind ME – it is merely psychological deconditioning.

Wessely and his 'esteemed colleagues' will be almost impossible to remove from their positions, meaning that the Medical Research Council will not fund for biomedical research, NICE won't change their Guidelines and The Department of Health, Science and Media Centre, Ministry of Defence and Kings College won't want to fire him because that means that they will have to admit that they were wrong all along and the evidence for ME being an organic disorder is correct – going as far back as the 1980's - when Cheney, Peterson, DeFreitas and significant others first found a Retrovirus involvement (same time as AIDS) as well as the destructive nature of the cancer-inducers.

That means that we must as a collective continue to put pressure on the Government to clean up their policies and remove any individual with vested psychiatric interests or gain. Someone is covering something up; we already know this judging by the existence of the Secret Files on ME.

The Countess of Mar at the House of Lords Debate on April 16th, 2002 stated that, “As Nero fiddled while Rome burned, so the Wessely School fiddles the facts while people suffer and die.” And later on she stated, “Simon Wessely, Michael Sharpe, Anthony David and Peter White, all psychiatrists, proceeded systematically to flood the UK literature with their own beliefs about non-existence of ME. They commandeered medical journals and the media. They became self-designated experts in medically unexplained symptoms such as ME, Gulf War syndrome and multiple chemical sensitivity. They have received disproportionate funding, amounting to over 5 million pounds for research into their own beliefs to the exclusion of virtually all research into organic causes. In 2004 they received a further 11.1 million pounds for ‘more research.’”¹³

Interviewed live by Rene Montagne, when asked why people thought sufferers don’t really have a disease, Dr Daniel Peterson, former medical director of the WPI, was clear: “I think the reason for that is the abnormalities of the immune system are initially very subtle. And if a physician does just routine testing – you find they’re normal. It isn’t until you look at the immune system that you realise there’s substantial dysregulation...It’s very similar to asymptomatic carriers of HIV. They look just fine until time passes and their illness evolves and more symptoms are found. **But I never felt this was predominantly a psychiatric disease or malingering. There was never any evidence to support that theory...**Once it was demonstrated that the patients had impairment of the natural killer cells function, regardless of what country they were in, we knew that there was immune impairment...Back in the 1990s, I was associated with Temple University and researchers (who) looked at the antiviral pathway...found very substantial abnormalities in the patients who had chronic fatigue syndrome. And the illness is totally compatible with a viral illness that just doesn’t go away”¹⁴

Sufferers are ANGRY that people are being left to die in an age of advanced medicine and technology.

One sufferer posted on the “New Scientist” website:

‘Red-faced’ – no, they should be sued for negligence. Sorry, but I was damn near killed by such idiocy so I have not the slightest sympathy for such bigoted physicians...I want several prominent persons responsible for this terrible abuse of millions of ill people across the globe criminally charged and tried for negligence...Many people have DIED because of this, either by direct abuse by doctors, or by disdainful refusal to aid, or actively preventing research into

¹³ Countess of Mar, debate in the House of Lords on ME.
<http://www.geocities.com/capitolhill/4277/countessmar.html?200616>

¹⁴ <http://www.npr.org/templates/story/story.php?storyId=113650222>

*physical causes. Sophia Mirza is only one such victim, most others just sank without trace as it was 'inconvenient' and their death or suicides were 'all their own fault as it was all in their heads'. But when a physician deliberately ignores his duties because of prejudice – that, sir is ABUSE. Imagine how an MS sufferer would feel if they were ignored, abused, even sectioned by the very physician who swore an oath to help them. And then the very person at the top of the pyramid of abuse was allowed to publish articles about MS..."*¹⁵

And some just commit suicide from all the never-ending isolation and pain, such as the latest tragic case of Annette Upton, who committed suicide weighing just 5 stone, another statistic of an ME patient whose healthcare system failed them.¹⁶

The psychiatric lobby are also sadly responsible for the current role of GPs in the diagnosis and treatment of ME/CFS patients, which is wholly inadequate. GPs, practise nurses and managers have little understanding of treatment options for ME/CFS, and NICE bar them from prescribing drugs that have been shown to be effective. A sobering thought.

When looking at the style of training being given to GPs, the views expressed below by nurses involved in a University of Manchester Study¹⁷ are hardly surprising. In fact they are truly nauseating.

'Early on in my training it was referred to as ME even though it isn't now. Erm, but it was seen as the malingerers last resort really for people who wanted to be more interesting than anyone else but, wanted not to do very much with their life. Erm, [pause], great deal of scepticism and, no time paid to it whatsoever, brushed over.'

'...depression, I think it's all related to depression...all were middle class women, erm, between the ages 30 and 50...I don't think it's a real condition'.

¹⁵ <http://www.meactionuk.org.uk/The-role-of-viruses-in-ME.htm>

¹⁶

<http://www.edp24.co.uk/content/edp24/news/story.aspx?brand=EDPOnline&category=News&tBrand=EDPOnline&tCategory=xDefault&itemid=NOED27%20Apr%202010%2019:16:16:747>

¹⁷ Practice Nurses' views of their role in the management of Chronic Fatigue Syndrome/Myalgic Encephalitis: a qualitative study

Carolyn Chew-Graham¹ ✉, Rebecca Dixon¹ ✉, Jonathan W Shaw¹ ✉, Nina Smyth² ✉, Karina Lovell³ ✉ and Sarah Peters² ✉

'I see the ones with rheumatoid arthritis...they come in and sit down and say 'oh I'll be alright'. They get on with it. Then, you know, you got these people chronic fatigue, and you think 'what's all that about?' You wanna shake people sometimes.'

'If all those come back normal [investigations] well, I don't know what they call them. They probably call them lazy fags... they probably classed as a waste of space... because [pause] people probably just look at them and think, oh you know he's just tired all the time: lazy...lazy bastards and wasting doctor's time.'

'you know what general like people are like, they're like skivers, err, who-who pretend that they have all these things because you can get a lot of stuff on the internet now, so they present themselves with lots of these symptoms and you think ah maybe that person's got ME or, or, or something similar.'

GPs have recently been trained on ME/CFS management using a succession of videos compiled by Dr Clare Gerada, vice chair of the Royal College of General Practitioners. Ironically, Gerada is also Simon Wessely's wife. This combination has resulted in propaganda that is truly disgusting.

In one video, Dr Gerada reconstructs a 'typical' GP consultation, where she plays the role of the doctor, with Alicia Deale playing the patient.

Below are excerpts from this video:-

"...can I have a little look at your diary?.....I think what your diary shows is again how important it is that we develop a consistent approach because what we talked about was that it's important that we break this association between activity and your symptoms we've talked before about the fact that you walk at the moment to the bus stop to go to work, how long extra would it be if you walk to the next bus stop?...."

*"...what we're trying to do here as I've said to you is to break this association between activity and your symptoms because equally if you feel rotten I still want you to do that activity...even if you're absolutely exhausted I still want you to do your **ten minute walk in the morning and the ten minute walk in the evening after work...***

Alicia Deale (Patient): *'Is that going to be safe?'*

Clare Gerada: *"**it will be safe** - all the evidence that we've put together and all the research literature shows that is absolutely safe you will not do yourself any harm..."*

They don't have evidence at all that doing such activity when feeling unwell is safe.

This video is still being marketed and it exploits them for what they really are. **Chalder, Tyree and their publisher make money from this as it is sold to GPs for their education.**

Tyree says: ***"they're trying to tell us it's physical and we're trying to tell them it's psychological."*** And Chalder agrees and says to just avoid the whole topic if a patient brings

it up.

In pacing **they counsel ME patients who are working overtime to stop going on benders at the pub several times a week!** They know how disabled and intolerant of alcohol ME patients are and yet they do this to give GPs the impression that patients are 'the undeserving sick.' In the last half of the second video they sum up all the lies.

Dr Chalder says she gets 70% of her patients better plus she thinks people should be dissuaded from contacting organisations like the ME Association and asking for lots of tests - merely keeping a diary, sleeping 8 hours a day and a bit of CBT will do the trick. Is she for real?

The whole tone of this video is deeply patronising and the pair of them clearly are propagating the worst form of propaganda. No wonder GPs don't take their patients seriously.

Nonetheless, the whole incident is a giant snare to ensure the sick are trapped and remain there. The Chief Medical Officer's Working Group was not even autonomous from vested interests — it was funded by The Linbury Trust (Lord Sainsbury), who has proudly shown public support and provided financial investment to psychiatrists of the Wessely School for years, to the sum of over £4 million (has nobody in Government asked why Lord Sainsbury, a staunch Blair supporter in who's era this policy was spawned, supports the *psychiatric* view of ME, despite so much published evidence to the contrary?).

When the Working Group was going through the most up-to-date research and understanding on aspects of clinical management of the illness, other than Wessely, White and Sharpe claiming that CBT and GET were the only effective treatments for managing ME, there were very few papers that focused on biomedical treatment regimens and research protocols such as Ampligen trials, antiviral trials, all of which were completed in the US prior to the NICE Guideline publication.

So — what are we left with in the literature about "treatment"?

Of *course*, we are left with papers spewed out (in truly awe-inspiring and voluminous proliferation) by the Wessely School on GA/CBT and on how successful this treatment modality is in curing this non-existent disorder.

Patients know that world expert on ME/CFS Dr Paul Cheney is right -

"The most important thing about exercise is not to have them do aerobic exercise. I believe that even progressive aerobic exercise, especially in phase one and possibly in other phases is counterproductive. If you have a defect in mitochondrial function and you push the mitochondria by exercise, you kill the DNA".

This is the exact opposite of what Wessely et al believe: they urge patients to undergo exercise programmes, claiming that such programmes are beneficial and safe.

People have died following such programmes, but because the evidence is "only anecdotal", it is ignored. Presumably no-one will heed it until there has been a replicated double-blinded, placebo-controlled trial proving that, dear me, patients *do die* from inappropriate interventions.¹⁸

THERE SHOULD BE CONSEQUENCES FOR THE PSYCHIATRISTS PUBLICIZING SCIENTIFICALLY INACCURATE RESEARCH ON A DEVASTATING NEUROIMMUNE DISEASE THAT AFFECTS MILLIONS.

And what about the psychiatric lobby's involvement with XMRV – a virus with the potential to infect millions of the health population, not least people with ME?

The Wessely School and the XMRV Scandal

It is worth noting that three days before the Mikovits et al article was published in Science, Professor Peter White, in collaboration with Dr Bill Reeves of the CDC, published a paper in which they described endophenotypes of CFS (which White talked about in his presentation at Bergen on 20th October 2009 – see below). According to Wikipedia, "endophenotype" is a psychiatric concept, the purpose of which is to divide behavioural symptoms into separate phenotypes with clear genetic connections. The relevance of this to the neuro-immune disease ME/CFS has not been explained, but White and Reeves et al concluded: "*The data do not support the current perception that CFS represents a unique homogeneous disease*"¹⁹

It's interesting to note that this is not the first time that the infectious nature of ME/CFS has been called into question.

In 1999, Vrije Universiteit Brussel, Brussels, Belgium discovered a link between CFS Patients and blood transfusions. A percentage of these patients developed a flu-like illness which began their CFS after having a blood transfusion. 9 out of 35 patients had an Rnase L pathway activation, which indicates the presence of viral infection.²⁰

So does this mean that the authorities have known about the potentially infectious state of ME for over a decade and done nothing about it?

¹⁸ Observations on the Chief Medical Officer's Working Group on CFS / ME

¹⁹ Population Health Metrics 2009:7:17doi:10.1186/1478-7954-7-17

²⁰ <http://www.mefmaction.net/Portals/0/...0and%20CFS.pdf>

On 8th October 2009, the premier journal Science published a paper online showing a direct link between a retrovirus and ME/CFS²¹ which sent shockwaves through the ME community and had the Psychiatrists running scared.

Wessely, using Imperial College's Professor Myra McClure as a scapegoat for the process, hurried through an XMRV study within weeks, publishing quite confidently in PlosOne²² that no virus was found and there was no link. In his article in New Scientist on 9th October 2009 (referred to above), Ewen Callaway noted Professor Wessely's position regarding the discovery of XMRV in CFS patients: "*Wessely points out that XMRV fails to account for the wide variety of other factors associated with the CFS, including childhood trauma... 'Any model that is going to be satisfactory has to explain everything, not just little bits' he says*".

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Theoretically, Imperial College ought to have followed the correct laboratory procedures to ensure that the Imperial College XMRV study was a true replication of the Lombardi Science study.

The Science XMRV research DID pass rigorous peer review - over numerous months.

The Science results were not only analysed at the WPI labs but repeated at the prestigious Cleveland Clinic laboratories and the National Cancer Institute.

On the contrary, the rushed Imperial College study was part-funded by Wessely's turf, the Institute of Psychiatry, therefore condemning it to Wessely's self-fulfilling prophecy of no links between any viral pathogens and CFS. It was also peer-reviewed over a maximum of 4 days by a journal that allows researchers to 'pay-to-publish'. Not only did the Whittemore Peterson Institute make a statement on the methodology of the study to Professor McClure²⁴, scientists and institutions from all over the world, including the CFIDS of America (??) have differentiated between the PLoS ONE and Science methods, falling down on the side of the WPI.²⁵

As pointed out by Suzanne Vernon, the techniques used in the PLoS ONE paper and the Science study differ – there is a key technical weakness that renders the Imperial College study null and void.

The most evident point is that Imperial College's patient definition did NOT follow the rigorous Canadian Criteria for ME/CFS AND Fukuda Criteria, as per the Science paper.

²¹ Detection of infectious retrovirus XMRV, in blood cells of patients with chronic fatigue syndrome. Lombardi VC, Ruscetti FW, Peterson DL, Silverman RH, Mikovits JA

²² <http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0008519>

²³ <http://www.meactionuk.org.uk/The-role-of-viruses-in-ME.htm>

²⁴ <http://www.investinme.org/Documents/WPI/WPI%20Statement%20McClure%2010-04.pdf>

²⁵ <http://www.cfids.org/cfidslink/2010/010603.asp>

Patients were selected from Wessely's own invented Oxford Criteria; a set of criteria created by and for psychiatrists - these criteria are far less rigorous and may include patients with fatigue as their only symptom. As such it allows far too many possibilities of inclusion of non-ME patients and serves no useful purpose, other than to aid the assertions of biased psychiatric groups who see ME as a somatoform disorder. They, therefore, serve no real useful or scientific purpose.

The patients were taken from Wessely's own clinic at Kings College. This is the enduring defect in a great amount of the research.

Given the evidence, it comes as no surprise that McClure and Co. did not find XMRV in any of these patients, who could have had any disease from depression to anaemia, not CFS. It is important that the Government are made fully aware of the serious nature of a retrovirus that could infect ten times more people than AIDS.

We urge the Government to fund more research on ME/CFS and XMRV! But please, and this is a deadly serious please, make a distinction between credible research and falsified, biased science carried out by Psychiatrists who have no business dealing with retrovirology.

In a reply to someone who wrote to him on 12th November 2009 asking for his response to the XMRV findings, Wessely replied: *"Could be a real breakthrough, even if I still don't understand how they made the leap from prostate cancer to CFS"*, which seems to indicate that Wessely remains ignorant of or else does not understand what Judy Mikovitz et al said: ***"both are linked to alterations in the antiviral enzyme RNase L"***, a link that was clearly explained by David Bell in his Lyndonville News, volume 6, number 2, October 2009:

"XMRV was first linked to human disease by Robert H Silverman, PhD at the Cleveland Clinic in patients with prostate cancer who also had a defect in the RNase L antiviral pathway. As this pathway has been known to be abnormal in CFS, it was reasonable to search for the virus in CFS". Wessely then seemed to deny the association with XMRV and cancer: *"I am worried that 20% of the CFS patients seem to have lymphoma (i.e. cancer), which might be fascinating for our knowledge of cancer but really isn't relevant for CFS"*. Apparently adopting the same stance as Bill Reeves in the US, Wessely continued: *"I would be very surprised indeed if others find rates of XMRV at the same level as this paper"*²⁶

Canada and Australia have banned blood donations. Belgium does not allow it. New Zealand's blood banks plan to reject donors with a record of ME/CFS. Recently the CFS Advisory Committee in USA, a Federal agency, recommended to the US Secretary of State for Health that donations from ME patients be banned.²⁷

²⁶ Co-Cure ACT: 12th November 2009

²⁷ http://www.hhs.gov/advcomcfs/meetings/agendas/cfsac20100510_agenda.html

A recent testimony at the CFSAC on 5th April 2010, stated that *“it would seem to me that XMRV associated neuroimmune disorders (XAND) are tentatively, **a matter of national security**, and require funding commensurate with this possibility.”*²⁸

Is the current Government going to give the Psychiatrists power to override a matter of **national security** by using their faulty non-scientific data as evidence?

To learn about ME/CFS, see the rigorous Canadian Criteria. A far cry from the vaguely fatigued everyday-Joes who populated Wesseley's "Failure to Detect" study. Everybody gets tired. ME/CFS is a completely different ball game – tragically, quite possibly in the retroviral league of HIV. Shame on you for propagating scientific hogwash!

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²⁸ http://www.hhs.gov/advcomcfs/meetings/presentations/cfsac_testimony_5_10_2010_anonymous_1.pdf