INVEST in ME



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Charity Nr 1114035

Mr Paul Bridge General Medical Council 3 Hardman St Manchester M3 3AW

Re Hearing of Dr Sarah Myhill - Case Reference: PB/C1-314994282.

20 April 2010

Dear Mr. Bridge,

Invest in ME is an independent UK charity campaigning for bio-medical research into Myalgic Encephalomyelitis (ME or ME/CFS), as defined by WHO-ICD-10-G93.3.

We heard recently of the hearing being set up to investigate the information on the web site of Dr Sarah Myhill.

It is known that there are ME/CFS patients who have been helped by Dr. Myhill's treatment regime. When there is a paucity of doctors who are knowledgeable about ME/CFS then it seems strange for the GMC to pick on one of those who does have substantial knowledge of the disease and awareness of the effects on patients and families.

The GMC case is without specifics so it is difficult to comment on exactly what the GMC need to investigate.

Therefore Invest in ME would like to comment on the consistency and the objectives of the GMC in bringing this case.

We do receive complaints of the way CBT and GET is being forced on ME/CFS patients as treatments for ME/CFS by the NHS doctors who just follow he NICE guidelines and treat ME as a lifestyle problem instead of a neurological disease as defined by the WHO. We wonder if the GMC are aware of the dissatisfaction by people with ME/CFS and their families of the treatment provided by the NHS for this neurological disease.

We constantly receive letters from the Department of Health stating that very little is known about ME/CFS and yet without doctors like Dr Myhill, who are willing to see ME/CFS patients and perform research and learn in the process, many patients would have little hope for a better future.

GPs in the UK generally demonstrate an overwhelming degree of ignorance toward ME/CFS – either disbelieving it exists, misdiagnosing other diseases in its place, failing to identify the potential consequences of severe ME/CFS and failing to spend any time in improving their education about the disease, such as attending biomedical research conferences or being acquainted with the latest biomedical research in to ME/CFS.

In five years of organizing and hosting an annual CPD-accredited International ME/CFS Conference in London, attended by the most renowned experts on ME/CFS throughout the world, relatively few healthcare professionals have attended the event. Recently we have invited the GMC to attend and even present at this year's conference. We are still awaiting a reply.

Why does the GMC not act on this ignorance regarding ME?

The GMC is responsible for the medical curriculum for students. In the standard reference book used by medical students ME/CFS is listed in the mental health category! This is despite the World Health Organisation and the UK government recognising the disease as a neurological illness under ICD-10 G93.3. Why does the GMC not act on this dangerous inconsistency?

Instead of prosecuting doctors like Dr Myhill the GMC should make sure that its own educational curriculum for doctors is up to date.

There is no comment from the GMC on the scandal relating to ME/CFS where children are routinely forced from their parents and coerced into performing dangerous exercise. There is no comment from the GMC when adult patients who are seriously ill with ME/CFS are sectioned when they refuse to participate in pointless Cognitive Behavioural Therapy or dangerous Graded Exercise Treatments.

Is it not hypocrisy from the GMC to try then to remove a doctor who has information on a web site which may benefit people with ME/CFS.

The GMC fails to provide comment on possible blood supply contamination from patients with ME/CFS, revealed after the October 2009 Science publication of the research on the XMRV retrovirus which was performed by the Whittemore-Peterson Iinstitute/National Cancer Institute/Cleveland Clinic in USA. Recently the Canadians banned blood donations from people with ME/CFS and from people who have had ME/CS. Yet we see no comment from the GMC.

Wherein lies the danger to the public? From a doctor who is actively trying to help people with ME/CFS or from an organisation entrusted with the education of healthcare professionals yet which allows misinformation to be promoted or does nothing when a threat to the public is apparent?

If the GMC chooses to withdraw Dr. Myhill's license to practice then the GMC must also investigate the dangerous advice given on the King's College web site regarding CBT and GET for people with ME. It must investigate the videos on that site which advocate exercise whatever the condition of the ME/CFS patient. The GMC must investigate the advice on the Barts web site where wheelchair aids for people with ME/CFS are frowned upon.

If the GMC have concerns about the information on Dr. Myhill's web site then surely the first course of action would be to discuss with Dr. Myhill. The GMC should then proceed to discuss with ME/CFS patient organisations. Only after this course of action should the GMC consider the draconian measure of removal of a doctor's license.

Yours Sincerely, Chairman and Trustees Invest in ME Charity Nr 1114035