Date

## Dear (name of MP)

I am contacting you as one of your constituents, using this form letter as I am too unwell to write a more personal one.

I suffer from M.E. (Myalgic Encephalomyelitis). Whilst the latest NICE Guidelines of 2021 have stopped the promotion of harmful Graded Exercise and Cognitive Behavioural Therapy, I'm concerned that the response from the Royal Colleges has been to continue promoting these harmful therapies for M.E. sufferers. Thus they are ignoring the worsening of brain and muscle function after exercise for M.E. patients. International medical opinion and patient surveys also demonstrate that Graded Exercise and CBT are at best ineffective and at worst cause deterioration of M.E. sufferers.

The M.E. International Consensus Primer (2011) demonstrates numerous tests which can be performed in aiding a diagnosis for M.E., mostly brain scans and immunological markers.<sup>3</sup> Yet none of these are available over here on the NHS.

The UK Government states that it recognises M.E. as a neurological disorder.<sup>4</sup> In addition there are over 9,000 international peer-reviewed papers demonstrating that M.E. is an organic disorder,<sup>5</sup> affecting all three nervous systems as well as the immune, endocrine, cardiac systems and causing vascular disruption.<sup>6</sup> The World Health Organisation has classified M.E. as a neurological disorder since 1969.<sup>7</sup> (The WHO is implemented as guidance for many illnesses such as Swine Flu and Covid 19, yet in practice is ignored by this country in its classification of M.E. as a neurological illness.)

I am concerned because after almost fifty years of the WHO classifying M.E. as neurological, a psychiatric agenda is pushing to rename M.E. as BDS (Bodily Distress Syndrome) and/or MUS (Medically Unexplained Symptoms) and have it transferred from WHO's neurological section to mental or behavioural disorders. This would be catastrophic for medical truth, for me personally and all M.E. sufferers.<sup>8</sup>

Reflecting on the above situation, Dr. Sarah Myhill has set up a campaign demanding a public inquiry into the medical abuse of M.E. sufferers (MAIMES). Children with M.E. are particularly at risk from unnecessary child protection orders.

## Please can you do one or more of the following to change this dire situation?

- Join or become aware of the APPG on M.E., chaired by Carol Monaghan (SNP).
- Sign up to Dr. Myhill's campaign, if you haven't already done so, calling for a UK public inquiry into the medical abuse of M.E. sufferers

P.T.O.

http://www.drmyhill.co.uk/wiki/Medical Abuse In ME Sufferers (MAIMES). You will be given a free book by Dr. Myhill called *Diagnosis and Treatment of CFS/ME* 

- Support the need for an M.E. diagnostic test
- Support the urgent need to change the Dept. for Work and Pensions' definition of M.E., which disgracefully categorises it as a psychosocial illness in contrast to the Dept. of Health's recognition of M.E. as neurological
- To ask the CMO to steer the current NHS M.E. clinics into biomedical, not biopsychosocial centres, wrongly influenced by the Royal Colleges persistence in promoting exercise to the contrary of NICE Guidelines.
- Write to the President of the Royal College of Physicians in London, requesting that
  they do not promote exercise for M.E. sufferers in line with recent NICE Guidance
  changes.

If you could act on either one or more of the above requests, you'll be doing me and thousands of other M.E. sufferers a huge favour. Your efforts will be a ray of hope amidst the prejudicial circumstances still surrounding M.E. Thank you.

Yours sincerely, (your name)

## 1 Joint statement in response to NICE guidance on ME/CFS (rcgp.org.uk)

- 2 A Physician's Guide to Myalgic Encephalomyelitis Chronic Fatigue Syndrome, The Nightingale Research Foundation, Vol. 1, Issue 7, revised, 1992, page 25. See also, Analysis Report by 25% ME Group March 2004, <a href="https://www.25megroup.org">www.25megroup.org</a> See also, Reporting of Harms Associated with Graded Exercise Therapy and Cognitive Behavioural Therapy in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Tom Kindlon, Journal of the International Association for CFS/ME, Fall Bulletin 2011, Issue 19(2):
- 3 Myalgic Encephalomyelitis Adult & Paediatric: International Consensus Primer for Medical Practitioners Bruce Carruthers, Marjorie van de Sande ISBN 978-0-9739335-3-6 page 11
- 4 Quote in writing from Ann Keen MP, Parliamentary Under Secretary of State, in a letter to Ann Widdecombe MP, 8 November 2007 for The Grace Charity for M.E. Also, the NHS was mandated to implement the WHO ICD-10 category of M.E. as neurological (see FN 4) on 1<sup>st</sup> April 1995 (letter from Tim Morgan, Dept. Health Customer Services Centre); referenced by Prof. Malcolm Hooper in his letter to Mr. Adam Butler, Dept. of Health 28<sup>th</sup> August 2011 responses-from-dwp-about-department-classification-of-me 1nov2011.pdf (margaretwilliams.me)
- 5 <a href="http://forums.phoenixrising.me/index.php?threads/the-significance-to-me-cfs-of-the-landmark-change-to-the-uk-law-on-consent.41989/">http://forums.phoenixrising.me/index.php?threads/the-significance-to-me-cfs-of-the-landmark-change-to-the-uk-law-on-consent.41989/</a> 9000 peer-reviewed papers on ME/CFS were used to uphold decisions by the Institute of Medicine and the National Institute of Health Pathways to Prevention, USA 2015
- 6 Disturbing Discrepencies In Statements Made By Prof. Simon Wessely in relation to M.E./CFS: some questions and answers of which the Gibson Parliamentary Inquiry Needs To Be Aware.

  Prof. Malcolm Hooper, Eileen Marshall, Margaret Williams 4th January 2006

  See also, A New and Simple Definition of Myalgic Encephalomyelitis and a New Simple Definition of Chronic Fatigue Syndrome, by Byron Hyde MD, May 12 2006, as presented at the London Conference
- 7 World Health Organisation International Classification of Diseases (ICD-11 8E-49; formerly ICD-10 G93.3)
- 8 http://forums.phoenixrising.me/index.php?threads/icd-11-status-reports-g93-3-legacy-terms-pvfs-bme-cfs.49549/