

Mr Frank Griffiths

Chairman

Leeds and York Partnership NHS Foundation Trust

1 May 2012

Dear Mr Griffiths

I write to you in my role of Chairman of Forward-ME (www.forward-me.org.uk) and as a long time campaigner on behalf of patients with CFS/ME in the House of Lords.

It has come to my attention that the Leeds and York Partnership NHS Trust is planning to reduce the services available to patients suffering from CFS/ME as a cost saving measure. I have been aware of the highly praised services for people with CFS/ME provided by your Trust for several years.

The newspaper article that I have seen indicates that you intend to withdraw the services of an immunologist and that you will be replacing a senior occupational therapist with a less costly member of staff.

I understand that you have agreed that there should be a month's consultation before you make your final decision.

The newspaper article claims that, as more is now known about chronic fatigue conditions and as the Trust claims that there has not been a case of misdiagnosis in years, employing an immunologist directly is no longer necessary. I note that the article refers to 'chronic fatigue conditions' and not specifically to CFS/ME which has another distinct category in the WHO ICD10. There has always been an association between viral infection and the development of CFS/ME and peer reviewed research done at Ninewells Hospital, University of Dundee has presented evidence of ongoing infection in both adults and children with CFS/ME. There is a large body of peer reviewed evidence of endocrine disruption including pituitary, adrenal and thyroid insufficiencies which do not show up on standard testing in people who are

given the blanket diagnosis of CFS/ME. In fact I have well documented cases of two such patients in the York area on my desk. Work at the Newcastle CFS/ME clinic, peer reviewed and published, has demonstrated that 40% of its patients who had been referred from GP's - did not have CFS/ME but could, in fact, be diagnosed with other serious conditions.

I am sure you will agree that it is essential that patients are given a correct diagnosis so that their symptoms can be treated if treatment is available. In the case of CFS/ME, it is still the case that not enough is known about causes and treatment. Cognitive Behaviour Therapy and Graded Exercise Therapy are management techniques – not cures, and they are known to be unhelpful for many patients with CFS/ME. I am aware of the publicity that accompanied the publication of the PACE Trial. I am also aware that there has been a great deal of scepticism of the published results and the fact that the authors have refused to release their raw data. There are several research projects underway funded by the MRC to investigate biomedical, as opposed to psychosocial, aspects of CFS/ME, including causation and effects.

It would be very reassuring to CFS/ME patients and their carers if you were to reconsider your decision to withdraw some of their services.

I look forward to hearing from you.

Yours sincerely

A handwritten signature in black ink on a light yellow background. The signature is cursive and appears to read 'Countess of Mar'.

Countess of Mar