Chronic Fatigue syndrome and Sleep; Initial findings from recruitment for the SAFFE study

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A large number of patients with Chronic Fatigue Syndrome (CFS) report disturbed and unrefreshing sleep, with consequent impact on daytime function. Paradoxically CFS patients report more disturbed nights following over-exertion, feeling frustratingly 'tired but wired'. There is also some evidence that the homeostatic sleep drive may be impaired in CFS with reports of slow wave sleep (SWS) and particularly very low frequency slow wave activity being diminished.

In response to a call from the MRC CFS/ME collaborative 2011, we were funded for a study to investigate whether enhancing SWS in these patients would improve both sleep and daytime function (SAFFE study). Sodium oxybate (SO) is a known enhancer of slow wave sleep and has an optimal psychokinetic profile for this challenge as it is short acting, ensuring that sedative effects the next day are minimised.

This ongoing study has a randomised, double-blind crossover design in which patients receive 3mg SO or placebo for 4 nights, with polysomnography to measure sleep, tests of daytime function the next day. We aim to recruit 12 patients, aged 25-65, meeting the diagnostic criteria for CFS according to both the Fukuda 5 and Canadian criteria. Exclusion criteria include clinically significant medical conditions, psychiatric disorders, respiratory and movement disorders of sleep, and taking psychoactive medications known to alter sleep.

To date, recruitment for this study has been difficult. Over 200 patients have volunteered; with 20% excluded in initial stages as taking psychoactive medications. Of those progressing to screening, 30% have been found to have undiagnosed sleep disordered breathing and 11% have been found to have psychiatric comorbidity. Based on initial observations, there appears to be poor identification of sleep disorders in patients with CFS, possibly due to the multiple pathways for diagnosis and care, and the symptoms of both fatigue and daytime sleepiness in this condition.