PE1690/A

NHS Lothian submission of 2 July 2018

The provision of support and treatment to ME sufferers in your respective health boards

Currently patients within NHS Lothian receive treatment through the ME/CFS rehabilitation service at the Astley Ainslie Hospital. A number of patients are reviewed at our Infectious Diseases unit when alternate causes of persistent fatigue are suspected.

Training, dissemination and awareness of relevant information and guidance among medical professionals, including GPs

NHS Lothian teach in accordance with Scottish Good Practice Statement on ME/CFS and NICE guidelines. Any updates from NICE in relation to the reevaluation of evidence will lead to a reconsideration of the practices of NHS Lothian for ME patients.

The evidence presented by the witnesses in relation to graded exercise therapy and cognitive behavioural therapy treatments.

As stated above NHS Lothian reflects the NICE guidelines and will be reconsidered when NICE re-evaluate the evidence, which is due to be published in 2020, with regard to our guidance and protocols.

NHS Lothian does not regard the creation of a Scottish centre of excellence for ME a priority at this time.

NHS Lothian do not accept all the evidence in the petition background information as accurate. In particular the Scottish Good Practice statement reviewed the claim that 1 in 4 people were house/bed bound with ME and found it to be unsupported. ME is now defined by the World Health Organisation ICD11 as 8E49 'post viral fatigue syndrome' under the heading 'Other disorders of the nervous system' with the synonyms 'benign myalgic encephalomyelitis' and 'chronic fatigue syndrome'. Evidence taken by a survey of all British neurologists did suggest that over 80% would not support the underlying view given of ME in this petition. NHS Lothian do not accept the petitioners criticisms of the PACE trial.