Name of petitioner
Emma Shorter on behalf of ME Action in Scotland

Petition title
Review treatment of people with ME in Scotland

Petition summary
Calling on the Scottish Parliament to urge the Scottish Government to review the level of support for people with Myalgic Encephalomyelitis (ME) in Scotland with a view to:
- Investing in biomedical research and creating a centre of excellence for ME
- Ensuring healthcare professionals' training and education materials reflect the latest scientific evidence
- Providing specialist care for patients and discontinuing the harmful treatments graded exercise therapy (GET) and cognitive behavioural therapy (CBT).

Action taken to resolve issues of concern before submitting the petition
Contacted MSPs and the Health Minister.

Petition background information
ME is a devastating disease that affects 21,000 people in Scotland and causes profound and disabling ill-health – one in four patients is home or bedbound, and quality of life is some of the lowest recorded of any chronic disease.

ME is defined by the World Health Organisation as a neurological disease (ICD 10 G93.3) but, following recent research, is often called a neuro-immune or multi system disease. It is estimated to affect more than 21,000 people in Scotland (see endnote 1), which is more than the number of people affected by Multiple Sclerosis (MS) and Parkinson's Disease combined. Due to decades of under-investment in biomedical ME research, there are currently no effective treatments available on the NHS and there are no ME specialist consultants in Scotland. Care is the responsibility of GPs, who do not receive training into how best to diagnose and treat ME, and have often been badly misinformed about the disease.

ME causes profound neurological (2), immunological (3) and endocrinological dysfunction. Research shows that people with ME score lower on health-related quality
Oxidative dysfunction. Research shows that people with ME score lower on health-related quality of life scores than people with most other chronic illnesses, including lung disease, heart disease and MS (4). It is estimated that 25% of ME patients, some of whom have been bed bound for decades, are severely affected unable to sit up, speak or feed themselves.

The estimated cost of ME to the UK economy is £8.8 billion per annum (5, 6), while the human costs are far higher. A recent survey of patients showed that over 65% of people with severe ME had been ill for 10 years or more. In Scotland, less than 10% of people with ME are in full-time paid work, education or training and only a further 24% are in part-time work, education or training (7).

Issues we would like to see raised by the review:

Research
Commitment to a programme of investment in biomedical research by the Scottish Chief Scientist Office, proportional to disease burden.

Creation of a Scottish Centre of Excellence for ME.

Education
Ensure that NHS Education for Scotland (NES) is complying with the classification of ME as neurological disease by WHO and updates its training material based on the latest scientific evidence, and ensuring that there are no conflicts of interest in the development and review of NES materials, with reference to previous studies, such as the PACE trial. Concerns about the PACE trial have recently been raised and, in a recent Westminster debate, Carol Monaghan MP said "When the full details of the [PACE] trial become known, it will be considered one of the biggest medical scandals of the 21st century” (8).

Care
Increased access to and investment in care for patients. Access for patients to physician-led services to provide appropriate advice along with recognition by GPs and medical practices that many people with ME require home visits due to the debilitating nature of the illness.

Removal of Graded Exercise Therapy and Cognitive Behavioural Therapy from the Scottish Good Practise Statement. Ensure that no healthcare services in Scotland offer Graded Exercise Therapy and Cognitive Behavioural Therapy. These therapies are based on the outdated bio-psychological model, there is a lack of evidence of efficacy for both CBT and GET and the majority of patients report adverse reactions.

Please support this petition. 21,000 people with ME in Scotland are in desperate need of better care and treatment. Some have been waiting for decades, for others it is too late.

ENDNOTES
2. Nakatomi Y et al. Neuroinflammation in Patients with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis: An C-(R)-PK11195 PET study 10.2987/jnumed.113.131045
6. £6.4 billion in 2006 equates to £8.8 billion in 2017 using the Bank of England
8. £6.4 billion in 2000 equates to £8.6 billion in 2017 using the Bank of England Inflation Calculator


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<td>Comments to stimulate online discussion</td>
<td>Would you like to see improved care and treatment for people with ME in Scotland? What level of support do you think the Scottish Government should provide for ME patients? Should Scottish Government funding be commensurate with disease burden?</td>
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