***From:***

***name***

***address***

***postcode***

***contact email.***

To: ***(insert name of MP)*** MP

I am writing to inform you of a deeply concerning delay to the publication by NICE of new guidelines for ME (Myalgic Encephalomyelitis, sometimes called Chronic Fatigue Syndrome). I am contacting you to ask for your help in ensuring timely publication.

Delete as appropriate:

***-I suffer from ME,*** and the condition has significantly affected my life. *(share personal story here if wished)*

***or***

***-I am a carer for an ME patient,*** and have seen the devastating impact that the condition has had on their quality of life. *(share personal story here if wished).*

ME is a debilitating condition which often occurs following an infection, leaving people with severely reduced energy, cognitive dysfunction, and significant pain, as well as other symptoms.

ME significantly impacts their quality of Life: many are unable to leave their homes. 75% are unable to undertake any work or education.

Up to 250,000 people in the UK have ME, including children and young people where it is one of the commonest cause of long term sickness absence from school

We hear through the ME charities that after 3 years of work, the guidelines had been delayed at the 11th hour.

I understand that the delay has been caused by at least two Royal Colleges refusing to implement the new guidelines. This is deeply concerning.

NICE is tasked with evaluating all relevant evidence and creating guidelines to ensure that patients are treated according to best current knowledge, not the preconceptions and biases of individuals clinicians.

I understand that the committee has undertaken a very thorough review of all the available evidence from clinical trials, experts and from patients. They reached a unanimous conclusion that there are no safe and effective treatments for the underlying disease process in ME in our current state of knowledge.

NICE’s objectives, methods and procedures are defined both in law, and their guideline development manual. These have been developed to ensure quality of it work.

Any attempts by external parties undermines the rigorous methods of NICE and threatens the principle of evidence based medicine.

I want to ask you therefore to support Forward-ME’s call to publish the new NICE guidelines on ME in-line with their established processes, to ensure that clinicians can implement best-quality care.

Please could you raise this issue with NICE leadership on my behalf, and support the letter to NICE that the APPG on ME has prepared (coordinated by Carol Monaghan MP carol.monaghan.mp@parliament.uk), which will be sent on Thursday 26th August at 5pm.

I would be grateful for your response to this letter.

Yours Sincerely,

***(insert name)***