



Email Example to invite MPs to join the All- Party Parliamentary Group (APPG) on myalgic encephalomyelitis (ME)

Dear *(insert MPs name)*,

As your constituent, I urge you **to join and attend the next meeting of the All- Party Parliamentary Group on myalgic encephalomyelitis (ME). This meeting will be held on (INSERT DATE) at (INSERT TIME).** Carol Monaghan MP will host this meeting so please contact her if you can attend.

(Add your personal message here: Tell your MP how long you or a loved one has had ME, and how the current situation in the UK has negatively impacted your care -e.g. CBT, GET, lack of access to mobility aids, lack of access to adequate investigations-, and how they can help you by joining the APPG on ME).

People with myalgic encephalomyelitis (ME) are disabled, dying and disenfranchised. ME affects 250,000+ people in the U.K and causes profound and disabling ill-health: one in four patients are housebound or bedbound and there are an estimated 400 patients in each constituency. The quality of life for people with ME is some of the lowest recorded of any chronic disease. Due to decades of under-investment in biomedical ME research, there are currently no effective treatments available through the NHS and we urgently need increased funding for biomedical research. Furthermore, immediate action must be taken to end the use of CBT and GET as treatments for ME. These treatments are based on debunked trials, are ineffective and potentially harmful, and contribute to the hostile environment of disbelief and neglect that sufferers face.

There's an urgent need to update training of GPs and medical professionals so that they are equipped with clear guidance on diagnosis of ME and appropriate management advice to reflect international consensus on best practice. In addition, all commissioning bodies must ensure medical, welfare and care services are accessible to people with ME, specifically including home visiting for those who are severely affected.

ME is estimated to affect 25,000 children in the UK, and is said to be the leading cause of long-term school sickness absence in the UK. Given the stigma people with ME face, families

will continue to meet accusations of misconduct and withholding of support. Without direct and decisive action, the mistreatment faced by children and families will continue on its established course. Families of children with ME face and overcome enormous challenges every day, both medically and educationally, due to widespread ignorance and a lack of effective treatment.

I urge you to attend this meeting and to stand up for people with ME as we are facing an urgent crisis.

Best wishes,

(Include your full name and address, including postcode)