12 May 2024

World ME Day

Dear [insert local MP name],

Following the recent Westminster Hall debate, led by Sir Sajid Javid MP, on Myalgic Encephalomyelitis (ME) on Wednesday 1 May, I am writing to you to further stress the urgent need for an increase in research funding into ME and for the full publication of the cross-Government Delivery Plan.

As you may already be aware, ME is a long-term (chronic) post-viral illness that causes symptoms affecting many body systems, more commonly the nervous and immune systems. Despite the condition’s prevalence, still so little is known about its causes and ultimate cure.

In the UK alone, there are an estimated 1.3m people living with ME or ME-like symptoms following a Covid-19 infection. Parallels have also recently been drawn between ME and Long-Covid, with some research indicating that at least 50% of people with Long Covid have symptoms that directly mirror ME. Given people with each illness present similar symptoms, finding effective treatments for one could help both groups.

One of the key issues lies in the urgent need for funding into research. Still so little is known about this disease which in turn, fuels a stigma widely felt by those living with it. There has been a distinct paucity of research into this disease when compared to other long-term conditions and, unless this changes, more and more people will develop ME and have their lives stolen by its symptoms.

Over the last 10 years, only £8.05m has been spent on ME research. If this were equitable to other illnesses, ME would have received £18.5m of the £5b spent annually on health research.

Furthermore, the world’s largest genetic study into ME, DecodeME, will soon be at the end of its funding cycle and without new funding commitments, people with ME will continue their daily battle with this debilitating illness without hope that research into finding a genetic cause and cure will ever progress.

It is also essential that the Government fulfils its commitment to release the full publication of the cross-Government Delivery Plan.

World ME Day 2024 marks exactly two years since Sir Sajid Javid MP first announced the Government’s intentions to develop the Plan, which has since been met with numerous delays. As the Minister for Health & Secondary Care outlined during the recent Westminster Hall debate, the Plan is “vital” to improve the experiences and outcomes for people with the ME, people who have been calling for recognition and urgent change for decades.

As my elected representative, I urge you to call on the Government to fulfil its moral duty to people affected by ME by committing funding to more, high-quality ME research and by releasing the full publication of the cross-Government Delivery Plan as a matter of urgency.

Yours sincerely,

[Insert your name]