



Act for ME

A pledge on ME

There is a critical need to accelerate research to improve the lives of at least 1.3m people with ME and ME-like symptoms. Over 30 years ago, Action for ME and others have called for adequate investment into research of post-viral conditions such as Myalgic Encephalomyelitis (ME). It has not been forthcoming and new post-viral diseases such as Long Covid are widespread.

We now find ourselves in a place where millions of people worldwide, including many in your constituency, are living in needless misery and the long-term health and economic costs are being laid bare.

You can help by meeting with us and pressing Government for immediate provisions to better understand, treat and potentially cure diseases such as ME.

Our aim is for a world without the devastation of post-viral diseases such as ME.

Join us in our calls for three key pledges the government can immediately make to improve the lives of those living with ME.

Our 3 key calls:

- 1** **Launch and full implementation of the Government's Delivery Plan:** In May 2022, the then-Health Secretary announced that the Government would release a delivery plan for ME/CFS. Since then it's delivery has been delayed on multiple occasions, leaving people with ME in limbo. We are calling for its immediate release and for its recommendations to be enacted in full.
- 2** **Equitable research funding:** Funding must be proportionate to the prevalence of post-viral diseases. We must leverage the UK's leading life sciences sector to support the prevention and treatment of ME. If funding for ME research was equitable with other illnesses, £18.5 million of the £5 billion spent annually on health research would be allocated to the disease¹. However, over the past 10 years only £8.05 million has been spent on ME research in total.
- 3** **Amend the Severe Disability Group criteria:** The Severe Disability Group is a set of criteria to help fast track disability claimants with the most severe conditions. While many people with ME should be part of this group, the current criteria state that the condition must be "confirmed or managed by a secondary care specialist." Given the severe lack of specialist ME clinicians across the country, the Severe Disability Group criteria must be amended to take this into account and ensure that people with ME can access the care and support they need and deserve.

¹ UKRI (2024), Available [here](#)



Please email actionforme@connectpa.co.uk to arrange a meeting and learn how you can help to create a future without ME for your constituents

