Red Alert for ME rally at parliament on Wednesday

Red Alert for ME: Belle and Sebastian's Stuart Murdoch will join campaigners at The Scottish Parliament on Wednesday calling for urgent action on pledged funding

Campaigners living with myalgic encephalomyelitis (ME) fear vital, long-awaited funding could be lost because of delays in allocating money to deliver specialist support projects.

The 2025-26 Scottish Budget included – for the first time – £4.5m to fund work across the country to support people with ME, Long Covid, and other similar conditions.

But campaigning group #MEAction Scotland is concerned that decisions between the government and health boards over the way the funding will be spent is not moving fast enough – and that could mean nothing moves forward in the budget year, or worse still, the money goes unspent.

#MEAction Scotland is to hold a rally outside the Scottish Parliament during ME Awareness Week to demand that funding pledged for people with the condition is spent urgently.

One of the speakers will be Stuart Murdoch, lead singer of Scottish indie band Belle and Sebastian, who lives with ME himself and is a long-time advocate, publishing an autobiographical novel about his experience with the illness last year.

Janet Sylvester, Trustee, #MEAction Scotland, said: "We're raising a red alert and calling on the government to get plans in place so that funding can start going out to health boards and begin to make changes to the dire situation in Scotland.

“We welcomed the budget commitment but it won’t mean anything if the money isn’t actually spent. Now that the budget year has started, the clock is ticking.

“Our major concern is that it will take so long to allocate the funding that the health boards will not have time to spend it in this financial year, as has happened with past Long Covid funding.”

The rally is taking place on 14th May during ME Awareness Week and is part of the Millions Missing movement – events organised by the ME community to draw attention to the millions of people around the world missing from society. #MEAction Scotland supporters have been contacting their MSPs and asking them to support the rally at Holyrood.

ME is a complex, energy-limiting disease affecting multiple systems in the body, which affects approximately 58,000 Scots.

However, there has been a frustrating lack of recognition and support to help those with the condition. The Scottish Government’s first outline for ME services was published by the Chief Medical Officer in 2002, just three years after The Scottish Parliament was formed. Subsequent reports were published in 2010 and 2020, which reinforced previous recommendations and found that little progress, if any, had been made. Since the Covid-19 pandemic, numbers living with the condition have grown due to overlaps with Long Covid, and an increasing number of people with Long Covid are now also being diagnosed with ME.

Karima Rahman, an #MEAction volunteer who lives with the condition, said: “We’ve had 20 years of reports on ME which haven’t led to change. Sadly, we saw previous funding for Long Covid services go mostly unspent by health boards – that can’t happen again.

“Scotland has no ME medical specialists, despite there being more people ill with it than other conditions such as MS and Parkinson’s. The government’s warm words must turn into urgent action.”

Protesters have asked MSPs from all parties to join them outside parliament this ME Awareness Week to listen to those affected and show their support for swift investment in services. Many people with ME will be too ill to join in person and will instead show their support online.

Photos below show scenes from a similar rally in 2022.


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