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Unveiling the Global ME Crisis: Urgent Appeals for Action from Advocates Worldwide

28 organisations globally join the World ME Alliance in demanding Recognition, Research, and Respect on World ME Day 2024

This World ME Day, 12th May 2024, marks **55 years** since the World Health Organization (WHO) officially acknowledged Myalgic Encephalomyelitis in the International Classification of Diseases in 1969. Yet there is still **no cure or treatment** for this devastating energy-limiting chronic illness.

The World ME Alliance and its 28 member organisations, including [your organisation] are calling on international health authorities to recognise the rocketing numbers of ME patients as a **global health crisis** and become a **#GlobalVoiceForME**.

The World ME Alliance conservatively estimates that **at least 55 million*** people globally are currently living with ME.

However, as COVID-19 infections continue unchecked, and without further epidemiological research, the true number of people with ME is unknown. A Jan 2024 [survey by the Center for Disease Control](#) (CDC) in the USA estimated prevalence at 1.3% which means the global ME population could be **over 100 million**.

Unlike the [39 million](#) people living with HIV, the [10 million](#) with Parkinson's or the [2.8 million](#) with MS, there are still **zero approved treatments** for these **55+ million** ME sufferers. Due to a dire lack of funding for biomedical research over the last 55 years, ME patients experience a drastically [lower quality of life](#) than other chronic conditions. Their wide range of disabling neuro-immune and cardiovascular symptoms leave 75% of them unable to work, and 25% housebound or bedbound.

They live in lockdown.

This May, the World ME Alliance is calling on allies to become a **#GlobalVoiceForME**, by reaching out to their national health authorities to demand recognition, research and respect for ME sufferers. An online event on Friday 10th May will showcase the advocacy of our member organisations across the globe. They are also drawing attention to the plight of those with Severe ME in less developed regions through a [#GlobalVoiceForME](#) portrait series. A video message compiled of submissions from around the world will be shared on social media on World ME Day - 12th May.

To find out more about ME or take action for World ME Day, visit www.worldmeday.org

About the World ME Alliance:

The World ME Alliance is composed of ME organisations from around the world. Its membership is made up of senior leads/representatives from national ME organisations, working together to achieve change for people with ME at a national and international level.

To learn more about the World ME Alliance, visit www.worldmealliance.org. Contact the World ME Alliance [via email](#) and follow the Alliance on [Facebook](#) or [Twitter](#).

For media inquiries only, contact:

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Information for the editor:

- Information about ME is available [here](#).
- Factsheet on ME available in multiple languages [here](#).
- Information about World ME Day is available at worldmeday.org
- Stock photos – use appropriate images to help decrease stigma. A selection is available on Getty [here](#).
- Royalty free photos depicting Severe ME are available [here](#).
- Case studies are available - please contact info@worldmealliance.org

** Before the pandemic, #MEAAction estimated there were between [15-30 million](#) people worldwide living with Myalgic Encephalomyelitis. In Jan 2023, a scientific paper in the journal Nature estimated that since the pandemic there were at least [65 million](#) people living with Long COVID, “with cases increasing daily”.*

*According to the paper, [more than half](#) of patients with Long COVID fail to recover and go on to develop ME. The World ME Alliance took the mean pre-pandemic figure of 22.5 million and added 50% of the Long COVID patients, 32.5 million, to arrive at their conservative estimate of **at least 55 million** currently living with ME globally. Research by the [US National Center for Health Statistics](#) found that in 2021-2022, 1.3% of adults had myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). If we extrapolate this finding globally, there could be up to 105 million people living with ME/CFS.*