

**European ME Alliance Statement
WHO Regional Committee Meeting for Europe
29-31 October 2024, Copenhagen, Denmark**

Agenda Item 9: Framework for resilient and sustainable health systems in the WHO European Region 2025–2030

Honorable Chair, Esteemed Delegates,

The European ME Alliance is a pan-European patient organization and the voice of people with myalgic encephalomyelitis (ME, also known by the acronym ME/CFS) in Europe.

We commend the aim of the **WHO Europe Framework for resilient and sustainable health systems 2025-2030** for people to trust that they will receive timely, adequate, and affordable care, which is exactly what they deserve.

This commendable objective is currently outside of the reach of people with ME/CFS, who are being left behind due to the dangerous lack of knowledge about the disease. The decades of neglect, stigma, trauma, and disbelief experienced by patients and carers has been discriminatory and a violation of their human rights.

The European ME Alliance Pan-European survey of over 11,000 patients from 41 European countries and 3 non-European countries, highlights the urgent need to recognize ME/CFS as a severe and debilitating physical disease, and to provide adequate medical care, financial support, personal assistance, and social services for the many sufferers who are so disabled they cannot work, perform daily tasks independently, or physically care for themselves.

The 2020 EU Resolution on ME/CFS stated that only 10% of the estimated 240 million people worldwide had been diagnosed. We believe the main reasons for this are because:

1. There is no European ME/CFS strategy, and practically no national strategy exists to address this illness and its unique and debilitating symptoms.
2. Research remains under-prioritized and under-funded resulting in the lack of discovery of diagnostic biomarkers.
3. This leads directly to ignorance about the disease, and consequentially to disbelief of patient-reported symptoms by the medical community despite the existence of clinical guidelines for its diagnosis, thousands of evidence-based scientific publications, and its recognition as a neurological condition by the WHO since 1969.

In addition, all patients require the safety of a legal and regulatory framework to protect their rights and allow access to unemployment and disability benefits – things people with ME/CFS are regularly denied.

Our hope lies with you in helping us to address this humanitarian crisis.

The European ME Alliance can support you through our network of international ME/CFS researchers, clinicians and patient organizations who, if properly funded, can work to improve the outcomes of patients and relieve the economic burden that ME/CFS places on national economies and health systems. Thank you.

- EMEA: <https://www.europeanmealliance.org/index.shtml>
- EMEA Pan-European Survey: <https://www.europeanmealliance.org/emeasurveyeu.shtml>
- 2020 EU Resolution on ME/CFS: <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52020IP0140>