European ME Alliance (EMEA)
Sankt Göransgatan 84 3 Tr, 112 38 Stockholm, Sweden
Reg. no. 802534-2752
info@europeanmealliance.org | www.europeanmealliance.org

European ME Alliance Statement
WHO Regional Committee Meeting for Europe
27-29 October 2026, Copenhagen, Denmark

Agenda Item 12: Progress Reports. European Regional Action Framework for Behavioural and Cultural Insights for Equitable Health, 2022-2027 (biennial progress report) (EUR/RC72/R1)

An Ethical Imperative to Protect Lives by Ending the Culture of ME Exclusion

While WHO/Europe's Behavioural and Cultural Insights (BCI) frameworks provide valuable approaches across health contexts, a profound policy gap remains concerning the participation, protection and inclusion of people living with Myalgic Encephalomyelitis (ME), sometime referred to as ME/CFS.

This is not merely an administrative problem. It is an issue of equality, dignity and human rights.

People living with ME and their organizations have reported distressing experiences within healthcare, including interventions they experienced as poorly adapted to their condition or continued despite reported deterioration. Such experiences often result in medical trauma, further disability and a profound loss of trust.

Patients who report harm must not be ignored, disbelieved or reduced to behavioural explanations. Patient-reported deterioration is clinically relevant information and deserves to be heard, documented, and independently reviewed. Biomedical uncertainty must never become a justification for disregarding informed consent, patient autonomy or reports of adverse effects.

People living with ME must also have access to effective legal protection, accountability and meaningful avenues for redress when their dignity, autonomy, safety or rights are compromised.

In the absence of a political mandate to require dialogue, health interventions inadvertently drive patients into deeper states of disability. Beyond the direct harm experienced, these individuals report insurmountable obstacles when attempting to access their constitutional right to legal protection. Because exertion intolerance is inherent to ME, it compounds the disability of those who attempt to engage in self-advocacy.

We therefore call on WHO Europe, European and international institutions, national governments, human-rights organizations and civil society to urgently strengthen mechanisms for the safe, accessible and meaningful dialogue, participation and protection of people living with ME.

We call on international organizations and civil society to creatively and urgently address the ethical crisis created by the ongoing exclusion, marginalization and reported public health system's traumatization of citizens living with ME.

People living with ME and its severely disabling symptoms should not have to risk further deterioration to obtain care, protection or justice.

The European ME Alliance made a statement on this topic at the 2024 WHO Europe Regional Meeting which can be found here: https://www.europeanmealliance.org/emea-news-whoe-241003.shtml

Thank you.