
EMEA Calls for the Inclusion of Myalgic Encephalomyelitis in the Implementation of the Political Declaration of the 4th UN High-Level Meeting on Noncommunicable Diseases

European ME Alliance Press Release

As Member States prepare to adopt a 'Political Declaration' at the 'Fourth United Nations High-Level Meeting (HLM4) on the Prevention and Control of Noncommunicable Diseases (NCDs) and the Promotion of Mental Health and Well-Being' on 25 September 2025, we urge governments to explicitly recognise **Myalgic Encephalomyelitis** (ME, also known as ME/CFS), recognised by the World Health Organization under ICD-11 code 8E49, as a serious, complex, and neglected **physical** noncommunicable disease that urgently requires coordinated, multisectoral action.

ME affects an estimated 240 million people globally ([2020 European Parliament Resolution on ME/CFS](#)), many of whom experience severe functional impairments, long-term disability, and a lack of access to appropriate medical care and social support.

Despite its debilitating nature and significant disease burden, **ME remains largely invisible in global and national health policy**, mistakenly hidden under different names and diagnostic criteria, underfunded in research, and consequently poorly understood in clinical care systems.

The **HLM4** on 25 September 2025 represents a vital opportunity for the United Nations and its Member States to demonstrate leadership by ensuring that ME is included in global and national health strategies aligned with the commitments in the Political Declaration.

The draft Declaration's emphasis on equity, multisectoral action, addressing the social determinants of health, and universal health coverage, offers a critical opportunity to ensure that people with ME are no longer left behind.

Our requests below to the UN, its agencies, and its Member States can be achieved by **integrating ME into existing global and national frameworks**. We ask for the implementation of our requests **with a Key Performance Indicator of 80% uptake by 2030, with progress reported annually**.

- **Commission ME impact studies.**

- The United Nations Economic and Social Council (ECOSOC) to formally recommend that Member States commission ME impact studies and use the data to integrate ME into national Universal Health Coverage packages, NCD strategies, policies, action

European ME Alliance

plans, and health system frameworks called for by the WHO Global Action Plan for the Prevention and Control of Noncommunicable Diseases.

- The World Health Organization to apply its Health Impact Assessment methodology specifically to ME, to provide actionable recommendations to strengthen health systems, research, and education.
- The WHO/United Nations Development Programme (UNDP) to undertake a global/regional ME assessment pilot.
- **Include ME in the implementation of national Disability Rights strategies** so patients' rights and ME's special needs have equal and equitable protection under national laws and the UN Convention on the Rights of Persons with Disabilities.
 - **Ensure all stakeholders understand that lack of providing support for patients, and the lack of recognition and accommodation of their special symptoms, causes an increase in their disability levels.**
- **Prioritise biomedical research for ME** within existing structures such as the Global Health Innovative Technology Fund and the WHO/UN Coordination Platform, given the lack of research funding for ME compared to the high disease burden for this neglected disease.
 - Researchers can join and support existing expert networks such as the [European ME Research Group](#) (EMERG) and the [Young/Early Career European ME Research Group](#) (Young EMERG) – initiated within the European ME Alliance patient organization.
- **Produce medical training and educational materials** on existing platforms such as the United Nations Institute for Training and Research (UNITAR) and the WHO Academy, to provide training to healthcare professionals and all stakeholders so they are equipped to provide patients with early diagnosis, pacing management techniques, appropriate care, as well as recognition and accommodation of their severely disabling symptoms.
- **Eliminate stigma and perpetuation of misinformation about ME** with global public health and education campaigns, including using the UN 'Verified' Initiative for digital-first national campaigns to combat misinformation online, and also the 'Pause' Initiative which encourages people to stop and verify information before sharing.
- **Strengthen ME health data collection and surveillance** through the WHO Global Monitoring and Surveillance System, to monitor progress and hold governments accountable.

To achieve the United Nation's Sustainable Development Goal of Universal Health Coverage, and target 3.4 of reducing premature mortality from noncommunicable diseases by one-third

by 2030, it is essential to address diseases like ME that have long been neglected, stigmatised, and marginalised.

In fact, due to decades of neglect, and lack of support, recognition, and accommodation for patients' severely disabling symptoms, **there is an elevated risk of suicide among individuals with ME.**

Recognition, accountability, and action for people with ME must be part of this global commitment.

References

1. [EMEA Proposal to EU](#)