

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

Agenda Item 2: The state of health in the WHO European Region

Honorable Chair, Esteemed Delegates,

The European ME Alliance is pleased to address WHO Europe and its Member States for the first time. We commend the great strides you are making to improve the health of European citizens.

We hope that moving forward we can work together to address the huge unmet needs of people suffering from myalgic encephalomyelitis – ME also known as ME/CFS - because they have been left behind, due to a dangerous lack of knowledge and misinformation about the disease that has real and serious negative consequences for patients.

Therefore, we are calling for a comprehensive and well-funded strategy on ME, because:

1. Patients' human rights are being violated due to disbelief, stigma and discrimination, leading them to be excluded from receiving assistance.
2. Universal health coverage is not meaningful for patients, because the health system has little to offer other than the management of some of their severely disabling symptoms. This is the result of the lack of research funding to identify biomarkers and curative treatments.
3. Many patients remain outside of the protection of the UN Convention on Rights of Persons with Disability, because without a diagnosis, their disability is not recognized.

The strategy should include:

- Official recognition of ME/CFS as a somatic illness as defined by the WHO.
- Implementing WHO's ICD Codes for ME/CFS in national health systems.
- Ensuring sufferers are not marginalized, and receive timely physical, financial, medical, and social support.
- Including the latest scientific evidence in medical curricula.
- Developing disease registries utilising the most up-to-date diagnostic criteria.
- Providing funding for biomedical research.
- Rapidly advancing development of Centers of Excellence.

Because governments have not taken ME seriously for decades, the European ME Alliance, which consists of patient organizations and charities, has had to organize and help fund research. However, we cannot do this alone. We need your help, and we need it now.

Thank you.

*European ME Alliance website: <https://www.europeanmealliance.org/index.shtml>