

## **European ME Alliance**

## Malmgårdsvägen 63 A, 116 38 Stockholm, Sweden Reg.Number 802534-2752

Email: info@euro-me.org web: www.euro-me.org

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## Agenda Item 9: A strategy on harnessing innovation for public health in the WHO European Region 2025–2030

Honourable Chair, Esteemed Delegates,

Myalgic Encephalomyelitis (ME, sometimes referred to as ME/CFS) devastates lives. Many patients spend years in darkened rooms, too weak to sit up, completely dependent on others for survival.

They are invisible — unseen, unheard — living in silence because social and health systems are not equipped to help them — and the United Nations Convention on the Rights of Persons with Disabilities is not implemented in a way that legally protects them.

This leaves millions of lives diminished, families broken and impoverished, and an epidemic of preventable suffering.

The WHO strategy on innovation in public health offers a turning point. Myalgic Encephalomyelitis is exactly where innovation is most needed.

Digital health and telemedicine can reach those who cannot leave their beds. Homebased care and personal assistance can prevent over-exertion and worsening disability levels.

We call for investment in a coordinated, collaborative European strategy of biomedical research to produce an infrastructure with the capacity to understand the disease, support patients, and develop effective treatments.

To include ME is to turn neglect into leadership. It is not only sound policy — it is a moral and scientific imperative. It embodies the values of this strategy: equity, inclusion, and the right to health for all.

The European ME Alliance will be pleased to work with WHO Europe Member States in establishing collaborative Centres of Excellence for ME throughout Europe.

Thank you.

- EMEA: https://www.europeanmealliance.org/index.shtml
- EMEA-supported ME/CFS Centre of Excellence in the UK: <a href="https://quadram.ac.uk/targets/me-cfs/">https://quadram.ac.uk/targets/me-cfs/</a>