

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

Agenda Item 12: Harnessing innovation for public health in the WHO European Region 2025–2030: preparing for a new strategy

Honorable Chair, Esteemed Delegates,

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

We commend WHO Europe for addressing complex health challenges that cannot be solved by traditional public health approaches, which we feel includes unjustly forgotten and neglected illnesses such as ME/CFS.

Many ME/CFS patients are house- or bedbound. Their situation fluctuates and is unpredictable. Their main symptom is called post-exertional malaise or PEM, which is the worsening of symptoms, or the onset of new symptoms, following even minor physical, mental or emotional exertion. This deterioration can happen immediately, or even days later. It can last for days, weeks, months, or years, and some patients may never recover from it.

Many patients are intolerant to light, to sound, to smell, and to chemicals. Many are unable to read or write, watch TV or listen to music. Many spend all day in bed in a dark and quiet room. Some very severe patients lack the energy to talk, and suffer intolerable pain. Others sadly resort to suicide. This disease affects families as carers, spending their lives covering the aspects of care that many European governments ignore.

For these reasons we need innovative ways for patients to receive timely medical and dental treatments in the protected environment of their homes – through mobile labs, or telemedicine – because travelling to the hospital can worsen their symptoms.

For those who can travel, most hospitals lack ME/CFS experts, and dedicated hospital rooms. Therefore, an innovative solution can be creating Centers of Excellence within existing research parks, staffed with interdisciplinary teams for both research and clinical care. Examples of such developing centers exist in the UK, Norway, and Sweden, and are currently funded mainly by European ME Alliance members.

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

Thank you.

- EMEA: <https://www.europeanmealliance.org/index.shtml>
- ME/CFS Developing Centers in the [UK](#), [Norway](#), and [Sweden](#)