

**European ME Alliance (EMEA) Statement
For the WHO Regional Committee Meeting for Europe
24-26 October, Astana, Kazakhstan**

Agenda Item 7b: Progress Report on 'Reaffirming commitment to health systems strengthening for universal health coverage, better outcomes and reduced health inequalities (EUR/RC68/R3)

Honourable Chair, Esteemed Delegates,

The European ME Alliance (EMEA) is a pan-European patient organization currently representing 18 European countries and growing. The Alliance gives a voice for people with Myalgic Encephalomyelitis (ME or ME/CFS) in Europe and is the European partner for facilitating high-quality biomedical research.

Reaffirming European countries' commitment to strengthening health systems for universal health coverage, better outcomes and reduced health inequalities is essential, because the disparity across Europe concerning the treatment and perception of people with ME/CFS is unacceptable and alarming.

As a non-communicable disease, ME/CFS often remains neglected, stigmatized, underprioritized, and under-researched despite it being a severe, long-term, complex, chronic, systemic disease, characterized by profound and persistent fatigue, low physical working capacity, autonomic, neurocognitive, immunological, and energy metabolism dysfunction symptoms (1,2,3).

Myalgic Encephalomyelitis has been recognized as a neurological disorder by the WHO since 1969 under ICD-10 and ICD-11 (4,5). Additionally, in 2015 the US Institute of Medicine issued a report confirming that ME/CFS is a real somatic disease to dispel the false belief that it is a psychosomatic illness (1).

The average prevalence rate of 0.2-0.4% is possibly the most common reference estimate. However, nobody really knows the actual figures, and seemingly, no action is being taken to correct this, despite availability of SNOMED tools to establish them accurately (6).

Statistics estimate 25% of ME/CFS patients are house- or bed-bound at some point during their illness. Many are intolerant to light, sound, smell, and chemicals. Many are unable to read, write, watch TV or listen to music. Some very severe patients cannot talk, have to be tube fed, and are intolerant to human touch. Others spend their days in a dark room or endure endless amounts of intolerable pain. Sadly, some

resort to suicide because their situation is unbearable and seemingly hopeless (7, 8, 9, 10). Unfortunately, only a small percentage of people with ME/CFS have been reported to have recovered (11).

Many people report their illness began after an infection (3). However, there are currently no simple clinically useful tests or biomarkers for the diagnosis of ME/CFS. This situation results, therefore, in many sufferers remaining undiagnosed or misdiagnosed, and perpetuates the low awareness and huge lack of knowledge about the disease. This feeds the continuing stigma surrounding ME, causing even more suffering.

In the absence of official recognition and funding, it has been left to EMEA member patient organizations to initiate and fund research in Europe. For that reason, EMEA has created:

- A 'European ME Research Group', with researchers from a dozen countries collaborating on biomedical research, and organizing meetings with researchers from the world's top institutes
- A 'European ME Clinicians Council', which is a similar network for clinicians.
- A 'European Early Career Researcher Network' with young European researchers collaborating with their US counterparts, allowing increased research capacity and awareness of the disease

As governments work to achieve universal health coverage, we urgently call on them not to leave ME/CFS patients behind, and to:

- Officially recognize ME/CFS as a somatic illness as defined by the WHO
- Ensure people with ME/CFS are not marginalized and receive timely physical, economical, medical care, social services, and support
- Include the latest scientific evidence on ME/CFS in medical curricula because awareness and knowledge of the disease is dangerously insufficient
- Provide much-needed funding of biomedical research to establish an understanding of the aetiology, pathogenesis and epidemiology of ME/CFS leading to improved diagnostics, symptom management and efficacious interventions for patients
- Rapidly advance development of Centres of Excellence for ME/CFS, possibly in existing research parks where more extensive facilities exist to expand research

Thank you

European ME Alliance Executive Committee

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