EMEA
European ME Alliance

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European ME Alliance Statement
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Honourable Chair, Esteemed Delegates,

The European ME Alliance (EMEA) represents people with Myalgic Encephalomyelitis (ME, sometimes referred to as ME/CFS).

ME is one of Europe's most urgent health crises.
Millions suffer worldwide. And yet, it remains largely invisible in global and national health policy.

Imagine living with fatigue so severe that you cannot feed yourself, communicate, or leave your bed. Add disbelief, stigma, and dismissive medical care on top of that. This is the reality for patients — and our survey of over 11,000 people confirms it is systemic across Europe.

ME patients urgently need support from healthy people to perform daily activities and administrative tasks, in order to avoid over-exertion and progression of the disease to more severe disability levels – because when the disease and its disabling symptoms are denied, people are left without assistance and become increasingly disabled until they are bedbound and unable to defend, or care for, themselves.

Including ME is not just compassionate — it aligns with WHO Europe's Second Program of Work. It strengthens Primary Health Care, addresses noncommunicable diseases, and harnesses data-driven innovation to ensure equitable access to care.

ME is exactly the kind of chronic, multisystem condition the EPW2 was designed to tackle — through integrated, person-centred, community-based care.

Inclusion of ME in WHO's Global Monitoring and Surveillance System would fill the critical evidence gap for effective public health planning and patient protection.

Applying WHO's Health Impact Assessment methodology would identify structural barriers — gaps in access, training, and care — just as recent reviews have done for Long Covid and chronic pain.

Some countries are already leading. Switzerland is developing a national ME strategy. WHO Europe can help other countries follow suit, providing guidance and coordination to scale up best practices across the Region.

Thank you.

• EMEA: https://www.europeanmealliance.org/index.shtml

• 2020 EU Resolution on ME/CFS estimates 240 million affected worldwide: https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=oj:JOC_2021_362_R_0002
• EMEA Pan-European Patient Survey: https://www.europeanmealliance.org/emea-pan-european-survey-pr-uk.shtml
• NICE Guidelines on ME/CFS: https://www.nice.org.uk/guidance/ng206
• Bateman Horne Center Clinical Care Guide: Managing ME/CFS, Long COVID, and Infection-Associated Chronic Conditions (IACCs): https://batemanhornecenter.org/wp-content/uploads/2025/05/Clinical-Care-Guide-First-Edition-2025-1.pdf