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European ME Alliance Statement
WHO Regional Committee Meeting for Europe
27-29 October 2026, Copenhagen, Denmark

Agenda Item 2: State of Health in the WHO European Region

Honourable Chair, distinguished delegates,

When we speak about the state of health in Europe, we must also ask:
Who is still missing from the picture?

Myalgic Encephalomyelitis, known as ME and sometimes referred to as ME/CFS, is an indicator of a structural blind spot in European health systems.

People with ME can experience severe or very severe disability, becoming housebound or bedbound and unable to access the services intended to help them. Yet appropriate clinical pathways remain scarce, specialist knowledge is limited, and patients still encounter disbelief, misunderstanding, and inadequate and often harmful treatment.

Research is essential, but patient safety, appropriate care, accessibility and dignity do not have to wait for a cure.

Patient experience reveals **three layers of harm**.

First, the harm caused by the disease itself.

Second, the psychological and social harm caused by disbelief, stigma and the repeated need to prove that their illness and limitations are real.

Third, the preventable physical harm caused by the public health system that requires people to exceed their physiological limits and harm their health in order to obtain care, disability assessment, and social service benefits.

This is a patient-safety issue and a human-rights issue, so we need accountability when preventable harm occurs.

Therefore, the state of health in Europe must be measured by how we care for those whom our health systems have historically neglected and failed to see.

Thank you.

European ME Alliance website: https://www.europeanmealliance.org/emea-news-whoe-RCP76.shtml