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European ME Alliance Press Release

FOR IMMEDIATE RELEASE

Why ME/CFS Deserves an EU Response European ME Alliance Calls for Coordinated EU Action on ME/CFS Using Existing Means

Stockholm, 8 August 2025

The European ME Alliance (EMEA), a grouping of European patient organisations and charities dedicated to supporting patients suffering from Myalgic Encephalomyelitis (ME, and also known as ME/CFS), is urging EU institutions to take realistic, coordinated action on ME/CFS, a disabling disease affecting over 2 million people in Europe.

In a new advocacy brief released this week, EMEA outlines four practical proposals for the European Union — each using existing EU mechanisms already applied to other diseases, such as rare diseases, Alzheimer's, and long COVID.

"We are not asking the EU to do the impossible," said EMEA chairperson Gracemarie Bricalli. "We are asking it to do what it already does — commission studies, coordinate research, support training, and protect rights — it just is not yet being performed for ME/CFS."

Key Proposals from EMEA's EU Advocacy Brief:

1. Commission an EU-wide Impact Assessment on ME/CFS

- To measure prevalence, economic burden, and gaps in care

- This assessment is justified by fragmented coding systems (e.g. SNOMED CT and ICD-11 not fully implemented across Member States)

2. Include ME/CFS in the Implementation of the EU Disability Rights Strategy

- Ensuring that people with ME/CFS are not excluded from social support and disability rights due to lack of diagnosis or visibility

3. Support Research Coordination Through Existing Networks

- Strengthen the work of the European ME Research Group (EMERG) via a COST Action or EU Joint Action

- Avoid duplication and build research capacity by using what already works

4. Fund Open-access Medical Education Materials via EU Programmes

- Use Erasmus+, EU4Health, or the EU Academy to develop open-access clinical training on ME/CFS

- Address the lack of awareness among healthcare providers

Background: An Under-Recognised Crisis

ME/CFS is a severe, chronic disease characterised by post-exertional malaise, neurological dysfunction, immune abnormalities, and often years of disability. The average time to diagnosis across Europe is nearly 7 years — if patients are diagnosed at all.

Despite its devastating impact on lives, families, and national economies, ME/CFS remains largely invisible in EU-level planning or strategy - a gap EMEA says must now be urgently closed.

EMEA is calling on:

- The European Commission to initiate an impact study and integrate ME/CFS into disability and training programmes

- Members of the European Parliament to support a coordinated response

- EU agencies and health programmes to recognise ME/CFS as a legitimate and urgent public health issue

“We do not need new structures. We need the EU to apply the same tools it already uses for other diseases. ME/CFS patients deserve visibility, support, and coordinated action — not more years of silence.”

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