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Coordinated EU Action on ME

One Page Summary

Why ME/CFS Deserves an EU Response

ME/CFS is a disabling, multisystem disease affecting 2 million+ people in Europe. Despite its impact, it remains largely invisible in EU data, policy, and funding. The EU can take realistic action - without creating new institutions or overstepping its competences.

What We Propose the EU Should Do

1. Commission an EU Impact Assessment on ME/CFS

- Via DG SANTE or the Joint Research Centre
- Identify prevalence, economic burden, care gaps
- Justified by the absence of harmonised data (e.g. underuse of SNOMED CT and ICD-11)

2. Include ME/CFS in EU Disability Strategy Implementation

- Reference ME/CFS in guidance to Member States and ESF+ funding calls
- Ensure people with invisible disabilities are not excluded from support

3. Coordinate Biomedical Research Using Existing Structures

- Build on the European ME Research Group (EMERG) and Young EMERG
- Fund via a COST Action, Joint Action (EU4Health), or CSA (Horizon Europe)
- Avoid fragmentation by strengthening what already exists

4. Fund Open-Access ME/CFS Training via EU Programmes

- Use Erasmus+, EU4Health, or EU Academy
- Respect national curriculum control while providing shared, evidence-based materials

What We Are Not Asking From the EU

We are **not** asking the EU to:

- Mandate clinical practice
- Interfere in national curricula
- Create new institutions

We **are** asking the EU to:

- Use proven EU mechanisms
- Fund and formalise existing efforts
- Treat ME/CFS as a legitimate public health challenge

More information - https://www.europeanmealliance.org/news-Q32025-002.shtml

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