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Coordinated EU Action on ME

Why ME/CFS Deserves an EU Response

Myalgic Encephalomyelitis (ME, sometimes referred to as ME/CFS) is a serious, multisystem disease that affects more than two million people across Europe. Despite its disabling impact and social costs, ME/CFS remains under - recognised in EU health planning, underfunded in research, and overlooked in disability support.

It would be easy just to call for this action or that action, knowing full well that nothing will be done.
This happens all of the time. However, we believe that change can occur.

We are not asking the EU to take on new powers or create new institutions. Instead, we propose a set of realistic, coordinated actions - using existing tools and precedents - that can meaningfully improve the situation for people with ME/CFS.

Our Four EU - Level Proposals

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

To address ME/CFS effectively, policymakers need a clear picture of its prevalence, severity, and social and economic burden. We call on the European Commission - through DG SANTE or the Joint Research Centre - to commission a structured impact assessment. This should measure disease prevalence across Member States, assess diagnostic delays, examine workforce loss, and quantify unmet care needs.

It may be argued that insufficient data exists to support such a study - yet that is precisely the problem. ME/CFS is systematically under-recorded due to inconsistent implementation of international health classification tools. For example, SNOMED CT, which includes detailed ME/CFS terminology, is not widely or uniformly adopted across the EU. Likewise, the ICD - 11 code 8E49 for ME/CFS, adopted by the WHO in 2019, is not consistently used in national coding systems.

These data gaps make the case for EU-level coordination even stronger. An impact assessment is not only justified - it is essential. The EU has previously commissioned such studies for rare diseases, long COVID, and neurodegenerative conditions. ME/CFS deserves the same attention.

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

People with ME/CFS frequently face denial of disability benefits, lack of workplace accommodations, and social exclusion - in part because their condition is invisible, misunderstood, and unrecognised in administrative systems. The EU Disability Rights Strategy 2021–2030 commits to improving access and inclusion for people with disabilities. However, ME/CFS is currently not reflected in the implementation of that strategy.

We propose that ME/CFS be explicitly referenced in guidance to Member States, European Social Fund Plus (ESF+) funding calls, and reporting on access to disability services. This does not require listing diseases in legislation - it simply means including ME/CFS as a case example in the same way other conditions such as autism or rare diseases are referenced in EU strategies and action plans.

This small step would send a powerful signal: **that people with ME/CFS are entitled to the same rights and protections as others living with disabling conditions**. It would also support alignment with the UN Convention on the Rights of Persons with Disabilities (UNCRPD), to which the EU and all Member States are party.

3. Coordinate Biomedical Research Using Existing Structures - Not New Ones

One of the most urgent challenges in ME/CFS research is fragmentation and capacity. Small, underfunded teams work in isolation, progress is slow, and findings rarely translate into clinical care. At the same time there is little to interest new researchers in entering the field and this stunts any further growth in capacity. While ME/CFS has appeared in occasional Horizon Europe calls, these one-off opportunities are insufficient to build lasting capacity or coordination.

Rather than create a new EU body or programme, we urge the EU to support the formalisation of existing networks, especially the European ME Research Group (EMERG) and the Young/Early Career European ME Research Group (Young EMERG) – initiated within the European ME Alliance to address these problems.

EMERG already brings together leading biomedical researchers from multiple EU countries and demonstrates that collaboration can easily be achieved. Young EMERG is creating new interest from early career researchers in Europe and is expanding. With proper EU support - such as a COST Action, a Joint Action under EU4Health, or a Coordination and Support Action (CSA) under Horizon Europe - EMERG/Young EMERG could become the central hubs for collaborative research, data sharing, and clinical translation. It could build collaboration amongst more research teams.

The EU has successfully used this model before. For example, the European Joint Programme on Rare Diseases (EJP RD) and the Joint Programme on Neurodegenerative Disease Research (JPND) have coordinated national efforts without replacing them. Supporting EMERG would follow that same, efficient logic: build on what already exists, and make it work better.

4. Fund Medical Training Resources via Existing EU Programmes

People with ME/CFS routinely report being misdiagnosed, dismissed, or subjected to harmful treatments due to lack of clinical knowledge. Education is crucial - but medical training falls under national authority, and EU institutions cannot mandate curricula.

That is why we propose a practical, indirect approach: the EU should fund and disseminate high-quality, open-access training materials on ME/CFS through existing platforms such as Erasmus+, EU4Health, or the EU Academy. These resources could be developed in collaboration with clinical experts, patient organisations, and researchers - and then freely offered to universities, continuing medical education (CME) providers, and professional associations across Europe.

This model has already been used for other conditions, such as dementia and antimicrobial resistance. It works because it respects subsidiarity while still achieving EU - wide impact. Coordinated content, offered voluntarily and free of charge, would help ensure clinicians receive consistent, science-based education on ME/CFS - without the need for top-down mandates.

Conclusion: A Smart, Collaborative EU Approach

We are not asking the EU to do what it cannot. We are asking it to do what it has done before - for other conditions and communities that faced similar neglect.

- Fund structured coordination through existing research networks

- Produce an impact assessment to inform policy
- Include ME/CFS in disability implementation guidance
- Support knowledge-building through voluntary training tools

These proposals are realistic, cost - effective, and within current EU competencies. They build on existing structures and mechanisms - not new institutions. We do not need reinvention – we need action.

It is time for ME/CFS to receive the coordinated European attention it urgently needs.

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