



European ME Alliance

EMEA Membership Charter of Principles

EMEA Membership Charter Version 1

August 2020

All European ME Alliance (EMEA) members are expected to uphold the following principles, and it is their responsibility to ensure that the principles are being honoured at all times.

- EMEA members will ensure that EMEA's news, resources and opportunities are disseminated within their organisations.
- EMEA members will work in a collaborative, non-competitive and respectful spirit as a network of organisations representing those affected by myalgic encephalomyelitis.
- EMEA members will work in accordance with EMEA's values, and within the framework of EMEA's policies and procedures.
- Members of the European ME Alliance endorse modern diagnostic criteria for myalgic encephalomyelitis. A list of the currently favoured criteria will be listed on the Alliance's web site.
- Members of the European ME Alliance endorse the UN Convention on the Rights of Persons with Disabilities.
- Members of the European ME Alliance promote the fact that myalgic encephalomyelitis is a neurological illness and listed at 8E49 of the World Health Organisation Index of ICD-11.
- Members of the European ME Alliance refer to myalgic encephalomyelitis as ME until evidence-based research causes that to change. However, the Alliance understands the practical necessity to use the composite term ME/CFS in some circumstances at the moment for ease of reference/standardisation.

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- Members of the European ME Alliance support biomedical research into myalgic encephalomyelitis that will lead to treatments and cures for this illness.
- Members of the European ME Alliance do not support promotion of any product or therapy for myalgic encephalomyelitis that has no acceptable evidence base and where the Alliance believes such product or therapy would be deleterious to the health of myalgic encephalomyelitis patients.
- Members of the European ME Alliance do not support the prescribing of cognitive behaviour therapy (CBT) or Grade Exercise Treatment (GET) as treatments for myalgic encephalomyelitis.
- Members of the European ME Alliance acknowledge the effect that myalgic encephalomyelitis has on individuals, their family and/or carers, and on relationships in general. As in other serious physical illnesses, EMEA recognises that people with myalgic encephalomyelitis may also require appropriate social, financial, physical and psychological support to manage their condition.
- The European ME Alliance has, as an objective, the preparation and promotion of a common set of documentation and terminology regarding myalgic encephalomyelitis, in all languages of Alliance members, for Alliance use and supplemented by local information. Members of the European ME Alliance will use this common set of documentation as a standard.
- Members of the European ME Alliance will work to eliminate the stigmas associated with myalgic encephalomyelitis, especially the misconception that it is a psychological illness rather than a

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biological one, which leads to trivialisation of the illness, missed or mis-diagnoses, and missed or non-treatment of those affected.

- Members of the European ME Alliance will work to protect patients who are too ill to defend themselves. They will engage in initiatives to increase awareness and understanding of myalgic encephalomyelitis, to set up inter- and multidisciplinary collaboration among different partners (researchers, clinicians, care facilities, patients, family, policymakers, etc.).
- Members of the European ME Alliance will advocate for health authorities to provide appropriate and timely care at all levels, even at home, as well as research and training for everyone involved with myalgic encephalomyelitis patients in order to improve, to the extent possible, the lives of people living with myalgic encephalomyelitis.
- Members of the European ME Alliance cannot speak on behalf of the Alliance without prior consultation and written permission from the EMEA Executive Committee.
- The European ME Alliance reserves the right to distance itself with an official disclaimer for actions taken by any Member that is in clear violation of agreed decision-making procedures, the EMEA Membership Charter or the EMEA Constitution.
- Members of the European ME Alliance will act in an ethical manner and not use their platform – including web site and social media postings – to advance a personal or discriminatory agenda, particularly in terms of race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.

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- Members of the European ME Alliance will avoid and disclose any real or apparent conflict of interest that may arise or any compliance risk.
- Members have a responsibility to disclose interests that might appear to affect their ability to act, decide, or participate objectively in EMEA meetings and activities.
- Members of the European ME Alliance will ensure adequate representation to EMEA's annual general assembly and strive to actively participate in/contribute to relevant EMEA-led meetings, events, initiatives, committees or sub-groups.
- Members of the European ME Alliance will avoid defaming or libelling EMEA, its members or the individuals involved; and will respect the ownership and copyright of EMEA and its members' materials and initiatives.
- Members of the European ME Alliance will ensure ongoing compliance with EMEA's membership criteria and will advise the EMEA Executive Committee immediately should the organisation no longer meet the requirements.
- Members of the European ME Alliance agree that all matters discussed within EMEA are confidential, unless specifically agreed otherwise.
- Members of the European ME Alliance support the work of the European ME Research Group (EMERG) in developing a strategy of high-quality biomedical research into myalgic encephalomyelitis with a collaborative, pan-European approach.
- Members of the European ME Alliance support the work of the European ME Clinicians Council (EMECC) in developing and



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improving clinical expertise in Europe with a collaborative, pan-European approach.