



Memorandum of Understanding

World  Alliance

World ME Alliance Memorandum of Understanding

1. Purpose

The purpose of this Memorandum of Understanding (hereafter referred to as “MOU”) is to set out mutually agreed governance expectations of all Parties involved.

2. What is the World ME Alliance?

The World ME Alliance is a collaboration between national ME organisations working together, and inclusively, as a global advocacy movement alongside the wider ME community.

3. Membership

3.1. Membership is open to any national or international ME/CFS organisation that wishes to join and agrees to work in accordance with the MOU and its values to further the World ME Alliance aims and objectives, subject to the below specifications:

- a. The organisation must have been established for at least 1 year.
- b. The organisation must be led by a board or other group of at least 3 people.
- c. The organisations must have people with lived experience of ME (either living with the illness or caring/supporting someone with the illness) supporting or leading their work.
- d. The organisation must have policy or advocacy objectives.
- e. The organisation must be able to demonstrate a sustained programme of work, beyond reporting on activities happening in their locality.

3.2. All members will have the opportunity to comment on new members joining as part of the joining process.

3.3. New members will be invited to a whole Alliance meeting before being granted membership.

3.4. Membership will be granted subject to consensus of the Founding Members. Each Founding Member will retain the right to veto new organisations joining. However this is expected to only be used in exceptional circumstances when the Founding Member believes the new member would undermine the vision, purpose or aims of the World ME Alliance or its ability to work effectively. The Founding Members are listed at the end of this document.

3.5. Organisations should be represented by their Chair or Chief Executive (or equivalent). In exceptional circumstances, attendance at meetings may be delegated to another senior person within their organisation. Meetings may be open to guests, as agreed by members.

4. World ME Alliance Vision

Our vision is a world without ME.



5. World ME Alliance Purpose

To ensure the needs of people with ME are met, now and in the future.

6. World ME Alliance Aim

Our aim is to secure an appropriate public health response from the World Health Organisation (WHO) and its Member States to:

- a. Recognise ME as a "serious, chronic, complex, and systemic disease that frequently and dramatically limits the activities of affected patients" (Institute of Medicine, 2015) and adopt measures to provide a global and co-ordinated public health response.
- b. Put in place transparency and a consultation process with ME organisations and people living with ME, on decisions related to ME
- c. Support accelerated biomedical research to develop better diagnostic methods and treatments for ME
- d. Ensure appropriate medical education for professionals working with people living with ME

7. World ME Alliance Strategic Objectives

- a. Promote and represent the needs of people with ME in international forums and platforms
- b. Make ME visible and influence policy-making with the United Nations and WHO
- c. Grow the global advocacy movement by working together and with other organisations
- d. Build capacity and strengthen national alliances and/or organisations
- e. Facilitate the creation of national alliances and/or organisations where none exist for people with ME in that country
- f. Through our member organisations, engage proactively with the ME community in our respective countries, to strengthen our work and achieve our objectives

8. World ME Alliance Values

The World ME Alliance values align with well-established global health principles and must be upheld by all members:

- a. Human rights-based approach – working together to advance and protect the rights of people with ME and secure equity
- b. Collaborative – work in partnership with the people with ME we individually serve, partners and the broader health community to achieve our purpose
- c. Transparent and accountable – effectively governed with clear accountability and decision-making through a collaborative agreement
- d. Independent – an independent body working to achieve mutually agreed purpose and objectives.

9. Governance & Decision Making

9.1. The Membership sets the strategic direction for the efficient and effective management of the World ME Alliance.



9.2. The Membership establishes, where necessary, committees or working groups with clear terms of reference and membership to fulfil ongoing or time-limited governance functions and in accordance with the MOU.

9.3. Where decisions are required and consensus cannot be achieved, member organisations will have one vote. Where two individuals from the same organisation work together to meet the obligations and activities of the World ME Alliance, the organisation will be allocated one vote.

9.4. The Chair and Vice-Chair posts are served in three-year terms of office, subject to Members' vote, up to a maximum of two consecutive terms of office or six years. An exceptional third term may be served for purposes of continuity but will require the full support of all Parties.

9.5. Meetings will be held at least quarterly. Where there is a need for a decision a minimum of three members must be present and where possible, those not present consulted before a final decision is made.

10. Logos

10.1. For the duration of this MOU, the World ME Alliance may use the logos of each of the members at no cost, provided that all logos are used together, and in accordance with the purpose of this MOU and any provisions made on the use of the logo by each Party.

10.2. If a member organises an event related to the World ME Alliance, the World ME Alliance logo must be used and the event organised in accordance with approval from members. If logos from members are to be used, branding must be pre-approved by all Parties.

10.3. A member cannot use the World ME Alliance branding for its own purpose without the prior agreement of members.

11. Termination of a Party

11.1. A member may leave the World ME Alliance at any time through written resignation made to the Chair which should be communicated to all Parties as soon as is practicably possible.

11.2. If a Party is considered by the other Parties not to fulfil its commitments, undermines or damages the World ME Alliance through its conduct or demonstrates business conduct by its representatives which is detrimental to the proper functioning and reputation of the World ME Alliance, such Party will be asked to account for its conduct to the membership.

11.3. A Party can only be expelled from the World ME Alliance following a majority vote of all members.



11.4. If a Party leaves the World ME Alliance, they will no longer be able to count themselves as a member, use its logo or name for its own purposes.

12. World ME Day

The World ME Alliance is the founder of World ME Day – an advocacy day first launched in 2022 and held on May 12th each year.

12.1. World ME Day aims to:

- a. Unify messaging around ME
- b. Expand the presence and impact of Alliance members actions to a global audience
- c. Support organisations to engage in a collectively chosen theme each year
- d. Create opportunities for individuals to engage in Alliance work and that of its members
- e. Aid organisations in reaching out to officials or official bodies in line with Alliance aims and objectives.

12.2. Alliance members agree to support this collective day of actions, promoting their work under the World ME Day banner.

13. Review

13.1. The MOU will be reviewed at least once every two years by the membership with any amendments proposed to all Parties for approval.

14. Dispute

14.1. Any action, whether arising before or after the end of this MOU, will be discussed between members.



Ratified on 7th June 2022

Founding Members

- **#MEAction**
- **Associació Catalana d'Afectades i Afectats de Fibromiàlgia i d'altres Síndromes de Sensibilització Central**
- **AQEM – Association québécoise de l'encéphalomyélite myalgique**
- **Action for M.E.**
- **The American ME and CFS Society**
- **Associated New Zealand ME Society**
- **Forward ME**
- **ME CFS Foundation South Africa**
- **Plataforma Familiars FM-SFC-SQM**
- **Solve M.E.**
- **Welsh Association of ME & CFS Support**

