



# Memorandum of Understanding

World  Alliance

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# 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 is not required to be legally formed
- e. The organisation must have policy or advocacy objectives.
- f. The organisation must be able to demonstrate a sustained programme of work relating to their policy or advocacy objectives, beyond reporting on activities happening in their locality.
- g. The organisation must support the World ME Alliance’s ME Core Evidence Review (in progress)
- h. The organisation’s representatives must agree and adhere to Code of Conduct (in progress) and agrees to participate in independent mediation if a conflict should arise

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 Strategic Leadership Board. Each member of the Strategic Leadership Board will retain the right to veto new organisations joining. However this is expected to only be used in exceptional circumstances when the member believes the new member would undermine the vision, purpose or aims of the World ME Alliance or its ability to work effectively.



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.
- e. Science-driven - recognise and promote strong scientific basis for accomplishing goals listed above

## 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. 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. Annual General Meeting (AGM)

- a. Frequency:
  - i. The World ME Alliance shall convene an Annual General Meeting (AGM) once a year to provide a platform for member organisations to come together.
- b. Purpose:
  - i. The AGM shall serve as a forum for discussing the progress, challenges, and future initiatives of the Alliance.
  - ii. Members will have the opportunity to review financial reports, receive updates on ongoing projects, and agree the strategic direction of the Alliance for the year ahead.
- c. Agenda:
  - i. The agenda for the AGM will include, but not be limited to, reports from the Strategic Leadership Board, financial statements, and discussions on strategic priorities for the upcoming year.



- d. Voting Rights:
  - i. Each Alliance member organisation shall have one vote during the AGM. Voting may include the election of board members, amendments to the memorandum, and other relevant matters.
- e. Attendance:
  - i. All member organisations are encouraged to participate in the AGM.
- f. Decision-Making:
  - i. Key decisions, where applicable, may be subject to a vote by member organisations present during the AGM. Decisions requiring approval outside the AGM may be conducted through a remote or online voting process.
- g. Minutes and Reports:
  - i. Minutes of the AGM, including decisions made and actions planned, will be documented and shared with all member organisations. Financial reports presented during the AGM will also be made available.

## 11. Co-Chairs and Vice Chair

- a. Roles and Responsibilities:
  - i. The Co-Chairs shall provide overall leadership to the Strategic Leadership Board, ensuring the effective functioning of the World ME Alliance.
  - ii. The Co-Chairs will preside over meetings, and guide strategic initiatives.
  - iii. The Vice Chair shall support the Co-Chairs in their leadership duties and assume responsibilities in their absence.
  - iv. The Vice Chair will actively contribute to strategic decision-making, collaborating with the Head of Advocacy and Communications, and undertake specific tasks or responsibilities delegated by the Co-Chairs.
  - v. Both the Co-Chairs and the Vice Chair shall represent the World ME Alliance and its member organisations in external engagements.
- b. Composition
  - i. The Co-Chair roles shall be reserved for the CEO's of the two member organisations that provide most funding for the World ME Alliance. This shall be reviewed at the point that a majority of the funding for the World ME Alliance comes from non-member organisations.
  - ii. Nominations for the Vice Chair position will be open to all member organisations, with an election held at the AGM.
- c. Term Limits
  - i. There is no term limit for the Co-Chair roles.
  - ii. The Vice Chair shall be elected for a term of three years with the possibility of re-election.

## 12. Strategic Leadership Board

- a. Purpose:



- i. The Strategic Leadership Board shall oversee key initiatives and decision-making processes of the World ME Alliance throughout the year.
  - ii. The membership of the World ME Alliance delegate decision making to the Strategic Leadership Board, in line with the strategic direction set at each AGM
  - iii. This Strategic Leadership Board may further delegate decision making to any of its members, including appointing members to lead on key work areas or initiatives.
- b. Composition:
  - i. The Board shall consist of the Co-chairs of the World ME Alliance, the Vice Chair, the Head of Advocacy and Communications, and five representatives from member organisations.
  - ii. One of the above positions will be reserved for an individual with lived experience of Severe ME, ensuring diverse perspectives. This individual may choose to delegate their responsibilities to a proxy as required.
  - iii. Advisory roles will be created at the discretion of the Board.
- c. Nominations Process:
  - i. Member organisations may nominate one of their members for the board, by email to the Head of Advocacy and Communications.
  - ii. Alliance member organisations shall each hold one vote to elect members of the Strategic Leadership Board, usually at the AGM.
  - iii. For the election to be valid, at least 50% of member organisations must vote. Candidates with a majority of votes will be appointed to the board positions available.
- d. Membership Roles:
  - i. Co-Chairs: Responsible for overall leadership and coordination.
  - ii. Vice chair: Supports the work of the co-chairs and shall assume the leadership role in their absence.
  - iii. Head of Advocacy and Communications: Manages the day-to-day running of the World ME Alliance, with a focus on advancing advocacy efforts and maintaining effective communication.
  - iv. Representatives: Play a proactive role in the operational management of the World ME Alliance, taking the lead in designated project areas and actively contributing to work of the Alliance.
- e. Term Limits:
  - i. Members of the Strategic Leadership Board shall serve a term of two years with the possibility of re-election.
- f. Responsibilities and Decision-Making:
  - i. The board shall collaborate to make decisions aligned with the strategic direction of the World ME Alliance as set at each AGM. Regular meetings will be held to discuss ongoing initiatives, address challenges, and plan future actions.



- ii. Where subgroups or working groups of the World ME Alliance are established, each shall have at least one representative from the Strategic Leadership Board among its members.
- iii. Members are required to commit to attending meetings of the Strategic Leadership Board every two months, to reading papers in advance of meetings, and to taking a proactive role in leading work of the Alliance. Exceptions to this will always be made for reasons of disability.
- iv. In the first instance, all decisions will be endeavoured to be made by consensus. Where this is not achievable, decisions can be made by a simple majority vote of all members. At least one of the Co-Chairs must be in favour for a decision to pass.
- v. Meetings will be quorate where half of members are present.
- g. Amendments and Review:
  - i. This section of the memorandum may be amended by a two-thirds vote of the existing board members. Periodic reviews shall ensure the effectiveness of the Strategic Leadership Board.

## 13. Logos

13.1. 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.

13.2. 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.

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

## 14. Termination of a Party

14.1. 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.

14.2. 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.

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





14.4. 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.

## **15. 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 12<sup>th</sup> each year.

15.1. 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.

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

## **16. Review**

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

## **17. Dispute**

17.1. In the event of a dispute between parties within the World ME Alliance, the initial step shall involve open and constructive discussions between the involved parties, aiming to reach a mutually acceptable resolution. Should resolution prove elusive, a designated member of the Strategic Leadership Board will mediate and collaborate with the disputing parties to facilitate an agreeable solution. In cases where resolution remains unattainable through mediation, the Strategic Leadership Board will review proposed resolutions and make a final recommendation for action. In all cases, the Co-Chairs shall make the final decision, ensuring fair and impartial consideration for the best interests of the Alliance and its objectives.

*Ratified on 19th June 2024*

