

The image features a blue background with twelve yellow stars arranged in a circle, similar to the European Union flag. In the center, there is a light blue map of Europe. Overlaid on the map is the text "Constitution of the European ME Alliance" in a bold, white font with a red outline.

**Constitution
of the
European
ME Alliance**

European ME Alliance

The Constitution of the European ME Alliance

Adoption of the Constitution

This constitution was first adopted at the European ME Alliance Annual General Meeting that took place on 9th August 2020 and came into effect immediately thereafter upon registration of the new Constitution with the legal authorities.

This version also replaced all previous versions of the Constitution.

The alliance and its property will be administered and managed in accordance with the following paragraphs of this Constitution.

Name, Headquarters & Language

- a) The association's name is **European ME Alliance** (and in this document it is referred to as EMEA).

The abbreviation for the alliance is EMEA.

- b) The association has its headquarters at

**European ME Alliance
Malmgårdsvägen 63 A
116 38 Stockholm
Sweden**

and is registered in Sweden with registration number **802534-2752**

and has national branches in all EMEA member countries.

- c) The Language for the European ME Alliance is English.

Alliance Purpose and Objectives

The European ME Alliance is a collaboration of ME organisations within Europe who have the common aim of promoting biomedical research into Myalgic Encephalomyelitis (known as ME or ME/CFS) and increasing awareness and



education regarding this debilitating neurological illness.

The Alliance will help collectively progress the understanding, perception and treatment of Myalgic Encephalomyelitis.

The European ME Alliance (EMEA) aims to:

- Establish correct recognition in Europe of myalgic encephalomyelitis as an organic illness requiring a strategy of biomedical research to determine the pathogenesis of the disease and develop treatments and cures.
- Establish correct and timely diagnosis of patients in Europe and beyond.
- Support the established specialised biomedical research centres for research/education/treatment into ME.

Objects of the Alliance

- a) The Alliance is non-profit making, non-commercial, politically independent and non-denominational.
- b) The Alliance's activities extend to the EMEA member countries.
- c) The Alliance aims to raise awareness of myalgic encephalomyelitis among the public, the professions, the business community and politicians.
- d) The purpose of the Alliance is to gather and disseminate information about myalgic encephalomyelitis and to establish contacts and influence policy towards ME in Europe
- e) The Alliance is intent on forging and facilitating links between the medical profession and research institutes working with myalgic encephalomyelitis in the individual member countries and throughout Europe.

All member organisations of EMEA agree to abide by the EMEA Membership Charter – detailed in the EMEA Members' Charter document. The EMEA Membership Charter will be updated, as required, and will remain up to date.

Membership

Membership is open to organisations who are interested in furthering the objectives and projects that are approved by the Alliance members and agree to abide by the objectives and principles mentioned above.

EMEA Membership application must be made by the official application process using the EMEA Membership Application Form. No one may be elected as an Alliance member at any General Meeting unless prior to the meeting the Alliance has received an official application from the applying group or individual.

The Alliance membership categories are:

- 1) Full Members
- 2) Probationary Members

- 3) Associate Members
 - 4) Sponsoring Members
 - 5) Honorary Members
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- a) Full members are representatives of a national ME charity or support group of any European country. The original member of any country will always be a full member. Full members will have voting rights in the decision-making forums held by EMEA.
 - b) Probationary members are those groups admitted to the Alliance in a General Meeting and who serve a period on probation in order to get used to the way that the Alliance works and to become acquainted with other members. Probationary membership lasts three months after which the Alliance decides the membership category to be accredited in the next General Meeting that is convened after the three-month period has passed.
 - c) Associate members are national and local groups who provide patient support for ME in a European country and who agree to the principles of EMEA. Associate members do not have voting rights in the EMEA forums but can participate in meetings organized by EMEA.
 - d) Sponsoring members are natural and legal persons who are interested in furthering the aims of the Alliance and in that way make special material contribution.
 - e) Honorary members can be persons who have earned special merit in furthering the aims of the Alliance. They become members after the approval at an EMEA General Meeting.

Membership is based on a due diligence and a vetting process by the EMEA Executive Committee and existing full members.

The EMEA voting rules apply (see Voting Rights chapter).

Approval for membership requires a two-third's majority of votes at a valid General Meeting.

EMEA full members decide at a General Meeting who shall become a member and which membership category will apply for the new member.

Refusal of membership will be notified to the candidate member with reason(s) for refusal. Appeal against this decision is possible and has to be addressed to the General Meeting within one month after notification. The General Meeting then decides with a two-thirds majority required, whether or not the candidate becomes a member.

EMEA will act on each application for membership within sixty days following receipt of the official application.



Membership is not transferable to any other group.

Rights and obligations of members

- a) All members are entitled to take part in the activities of the Alliance and to avail of the services provided by the Alliance.
- b) Full members have a seat and a vote right at the General Meeting.
- c) Full members have also passive/proxy voting rights, which includes voting digitally. Proxies may be appointed in writing which has to be produced to the Secretary before the General Meeting commences.
- d) Associate, sponsoring and honorary members have only a seat at meetings, but not voting rights.
- e) Membership fees are charges as laid out in the EMEA Membership Fees Document. These fees may be revised by decisions made by the full EMEA Executive Committee and agreed by a vote at a General Meeting where the topic is on the agenda. Changes will then be minuted and made to the EMEA Membership Fees Document.
- f) All members are obliged to abide by the Constitution of the Alliance and the decisions of EMEA Executive Committee and the General Meetings.
- g) All Alliance members shall agree to sign the EMEA Membership Charter and agree to abide by its principles.
- h) All members are expected to treat all matters discussed within EMEA activities as confidential, unless stated otherwise and agreed by members.

Termination of membership

- a) Membership will be terminated by:
 - Resignation
 - Expulsion
 - Dissolution of legal entities
 - Cancellation of membership
- b) Resignation does not exclude the fulfilment of the member's membership or other obligations in the Alliance for the ongoing year.
- c) Expulsion from the Alliance requires a unanimous decision in a General Meeting and is only permissible for grave reasons, such as not abiding by the Constitution of the Alliance or not abiding by the EMEA Membership Charter or any other written rules approved by EMEA Executive Committee or the General Meeting. Expulsion of a member group shall take effect at the time the decision is notified stating the reasons. An appeal against the decision is possible, which has to be sent to the EMEA Executive Committee within one month after notification. A Special General Meeting will then be

formed and the member has the right to defend themselves. The General Meeting may decide, with two-thirds majority, that the member may continue its membership. During the time from notification of membership termination until the decision of the General Meeting the membership of the member will be suspended.

- d) Membership termination from the Alliance requires a unanimous decision of the full EMEA Executive Committee. Termination is permissible if the member is not able to fulfil the obligations as a member and is not able to pay its annual membership fee. Termination will take effect at the time the decision is notified to the member in writing. An appeal is permissible.
- e) If a member group ceases to exist then that group's membership in the Alliance will be automatically terminated.

Chair

- a) General Meetings shall be chaired by the person who has been elected as Chair of the Alliance, or a substitute nominated by the Alliance Chair.
- b) If the Alliance Chair or the substitute nominated by the Alliance Chairs is not present within thirty minutes of the time appointed for the meeting, an Alliance member nominated by the Alliance members shall chair the meeting.
- c) If no Alliance member is willing to accept the nomination to chair the meeting within the following fifteen minutes then the meeting will not proceed.

Secretary

The Secretary is entrusted with the correspondence of the Alliance and keeping records of all the Meetings and reports them to the General Meeting.

Treasurer

The Treasurer is entrusted with finances of the Alliance and is required to draw up a report on the Alliances activities and the accounts balance sheet and to submit it to the General Meeting.

EMEA Executive Committee

- a) The Alliance and its property shall be managed and administered by an EMEA Executive Committee comprising the Alliance members elected in accordance with this Constitution.
- b) The EMEA Executive Committee shall consist of the following:
 - The Chairperson

- The Secretary
 - At least four other Alliance members
- c) The EMEA Executive Committee members are elected in the Annual General Meeting in the following way:
- Each EMEA Executive Committee member is elected for a period of service of two years
 - The period of service for EMEA Executive Committee members will be staggered with one half of the EMEA Executive Committee being elected for a two-year period in any AGM; then in the following year's AGM the other half of the EMEA Executive Committee will be elected for a two-year period.
- This will result in overlapping terms and provide continuity within the EMEA Executive Committee.
- d) Only full members of the Alliance may be elected as EMEA Executive Committee members.
- e) The Founding Alliance members and the first EMEA Executive Committee members shall be those persons elected as Alliance members and EMEA Executive Committee members at the meeting at which this Constitution was originally adopted.
- f) The EMEA Executive Committee will conduct the day-to-day running of the Alliance.
- g) The EMEA Executive Committee can decide to join other organisations, provided that all member societies are advised one month in advance and given the chance to comment on the proposed decision. If there is not agreement from the members on the decision to join an organisation, the Executive Committee can call a Special General Meeting to put the decision to an official vote.
- h) The EMEA Executive Committee is competent to fulfil all tasks required of the management of the Alliance so far as it does not belong to the tasks of the General Meeting.
- i) The EMEA Executive Committee is qualified to invite advisory members.
- j) The EMEA Executive Committee meetings shall be convened at least three times each year. The meeting may take place using electronic means in order to avoid unnecessary travel costs. At least one meeting per year must take place with all attendees physically present in the same location, unless extreme conditions exist such as epi/pandemics, acts of war or other uncontrollable events that are beyond members' control. Meetings shall be notified, stating the agenda and all papers involving the agenda. The

Secretary sends the notification, after consulting the Chair, at least six weeks before the meeting is scheduled to take place.

- k) The minimum EMEA Executive Committee will be composed of the Chairperson, the Secretary plus at least four other EMEA Executive Committee members.
- l) The composition of the EMEA Executive Committee has to be representative regarding the composition of the full members in the General Meeting.
- m) If for some reason the EMEA Executive Committee consists of less than six members, the EMEA Executive Committee is obliged to convene a General Meeting to elect replacements. During this period the EMEA Executive Committee is still competent to settle current affairs.
- n) The EMEA Executive Committee is obliged to hold a record of all members.
- o) The EMEA Executive Committee is obliged to make minutes of all EMEA Executive Committee meetings.

General Meetings

- a) The Alliance held its first General Meeting within twelve months of the date of the adoption of this Constitution.
- b) An Annual General Meeting must be held in each subsequent year and not more than fifteen months may elapse between successive annual general meetings.
- c) All General Meetings other than Annual General Meetings shall be called Special General Meetings.
- d) The Alliance members may call a Special General Meeting at any time.
- e) The Alliance members must call a Special General Meeting if requested to do so in writing by at least five members or one-third of the membership, whichever is the greater. The request must state the nature of the business that is to be discussed. If the EMEA Executive Committee fails to hold the meeting within forty-eight days of the request, the members may proceed to call a Special General Meeting but in doing so they must comply with the provisions of this Constitution.
- f) A General Meeting may be called by shorter notice, if it is so agreed by all the members entitled to attend and vote.
- g) The notice must specify the date, time and place of the General Meeting and the general nature of the business to be transacted. If the meeting is to be an annual general meeting, the notice must say so.

- h) The General Meeting is convened by the EMEA Executive Committee, who will give notification at least six weeks before the appointed date. The notification will be accompanied by the agenda and all paperwork involved.
- i) No business shall be transacted at any General Meeting unless a quorum is present.
- j) A quorum is five members entitled to vote, including proxy votes received by the Secretary, upon the business to be conducted at the meeting.
- k) The authorised representative of a member organisation shall be counted in the quorum.
- l) If:
 - 1) a quorum is not present within half an hour from the time appointed for the meeting; or
 - 2) during a meeting a quorum ceases to be presentthe General Meeting shall be adjourned to such time and place as the Alliance members shall determine.
- m) The Alliance members must reconvene the meeting and must give at least seven clear days' notice of the reconvened General Meeting stating the date, time and place of the meeting.
- n) If no quorum is present at the reconvened meeting within fifteen minutes of the time specified for the start of the meeting the members present at that time shall constitute the quorum for that meeting.
- o) The General Meeting has full authority of the Alliance except for authority given by law or this Constitution of the Alliance to the EMEA Executive Committee
- p) The General Meeting consists of all full members. Each full member may have a maximum three representatives.
- q) The General Meeting will be held at least once a year. The Alliance year is equal to one calendar year.
- r) Duties of the General Meeting:
 - Election and Discharge of Auditors
 - Approval of EMEA Executive Committee's Activity Report
 - Approval of Financial Report
 - Budget for the next year including the membership fee

- Discharge of EMEA Executive Committee members for the past year
 - Election of EMEA Executive Committee members for the coming year.
 - Approval of new members
 - Resolution on changes of the Constitution
- t) The General Meeting will be presided by the Chairperson or in his/her absence, by the Secretary.
- u) Unless stipulated otherwise in the rules of the Alliance, decisions of the General Meeting shall be reached by a simple majority of votes. If there is an equal division of votes there will be a second written ballot. If the votes are still equal, the proposal concerned is denied. In connection with membership, documentation, acceptance of documentation of a principle nature, requires a two-thirds majority.
- v) Every member country has one vote (according to the Voting Rights section). Proxies may be appointed in writing which has to be produced to the Secretary before the General Meeting commences.
- w) The EMEA Executive Committee is obliged to make minutes of each General Meeting.

Adjournments

- a) The members present at a meeting may resolve that the meeting shall be adjourned.
- b) The person who is chairing the meeting must decide the date time and place at which meeting is to be reconvened unless those details are specified in the resolution.
- c) No business shall be conducted at an adjourned meeting.
- d) If a meeting is adjourned by a resolution of the members for more than seven days, at least seven clear days' notice shall be given of the reconvened meeting stating the date time and place of the meeting.

Voting Rights

- a) Each member country shall have one vote for any meeting.

Where one member country has more than one full member then the vote for each voting member of that country within anyone meeting will be proportionately reduced by a percentage corresponding to the number of voting full members from that country.

Example 1

Member country x has two full members voting in one meeting.
The voting rights for each member of that country in that meeting will be 1/2 of one vote

Example 2

Member country x has three full members voting in one meeting.
The voting rights for each member of that country in that meeting will be 1/3 of one vote.

Example 3

Member country x has four full members voting in one meeting.
The voting rights for each member of that country in that meeting will be 1/4 of one vote.

etc..

- b) At meetings if there is an equality of votes the person who is chairing the meeting shall have a casting vote in addition to any other vote he or she may have.
- c) Since the nature of the illness (ME/CFS) means that some members may be unable to attend the Meetings, the EMEA Executive Committee may arrange postal or digital ballots and/or proxy voting to enable full participation in vital decision making.

Powers of Alliance members

The Alliance members must manage the business of the Alliance and they have the following powers in order to further the Alliance Objectives (but not for any other purpose):

- a) To raise funds to support the activities of the Alliance and research into ME/CFS.

In doing so, the Alliance members must not undertake any substantial permanent trading activity and must comply with any relevant statutory regulations;

- b) to co-operate with other voluntary bodies and statutory authorities and to exchange information and advice with them;
- c) to establish or support any charitable trusts, associations or institutions formed for any of the purposes included in the Objectives;

- d) to obtain and pay for such goods and services as are necessary for carrying out the work of the Alliance;
- e) to open and operate such bank and other accounts as the Alliance members consider necessary (all cheques must be signed by two Alliance members).
- f) to invest funds and to delegate the management of funds in the same manner and subject to the same conditions as the Alliance members of a trust are permitted to do within their respective countries;
- g) In financial matters the Alliance will be represented by the Chairperson and the Treasurer. If they are not able to act, they can authorise other EMEA Executive Committee members.
- h) To do all such other lawful things as are necessary for the achievement of the Alliance Objectives;
- i) No alteration of this Constitution or any special resolution shall have retrospective effect to invalidate any prior act of the Alliance members.
- j) Any meeting of Alliance members at which a quorum is present at the time the relevant decision is made may exercise all the powers exercisable by the Alliance members, but not powers related to membership status and fees or EMEA Executive Committee responsibilities.
- k) To inform relevant policy makers, practitioners and the general public of:
 - a. the extent and complex nature of ME/CFS
 - b. the effect ME/CFS has on individuals, their family and/or carers, and on relationships in general
 - c. policy recommendations that provide solutions to the challenges that the ME patients and carers face
- l) To encourage and support further research into ME/CFS and to disseminate to the public.

Representatives of Other Bodies

- a) Any organisation that is a member of the Alliance may nominate any person to act as its representative at any meeting of the Alliance.
- b) The organisation must give written notice to the Alliance of the name of its representative. The nominee shall not be entitled to represent the organisation at any meeting unless the notice has been received by the Alliance. The nominee may continue to represent the organisation until written notice to the contrary is received by the Alliance.

- c) Any notice given to the Alliance will be conclusive evidence that the nominee is entitled to represent the organisation or that his or her authority has been revoked. The Alliance shall not be required to verify whether the nominee has been properly appointed by their organisation.

Finances

The finances of the association can consist of:

- a) Membership fees of members
- b) Membership fees of extraordinary and sponsoring members
- c) Subsidy or grants by any other organisation on a national, European, or global level
- d) Gifts, legacy or testamentary disposition
- e) Any other means
- f) The membership fees, or any change of them, have to be proposed on the agenda of the General Meeting and have to be approved by the General Meeting
- g) The membership fees will be paid in Euros within 30 days of receipt of the annual invoice

Auditor

An auditor is elected by the General Meeting for a period of two years. Before a General Meeting the auditors shall inspect all the accounts and report thereon to the EMEA Executive Committee and the assembled members and/or explain the report.

Alteration of the Constitution

- a) A decision for alteration of the constitution can only be made by the General Meeting. A proposal for alteration has to be prepared by the EMEA Executive Committee and put on the agenda of the General Meeting. For alteration a two-third majority of the votes is needed. If no quorum is reached, the proposal automatically will be placed on the agenda of the next General Meeting. Between these two General Meetings stands a period of at least six months.
- b) The notification for this General Meeting must be sent to all members at least six weeks before the General Meeting, accompanied by the proposed alterations to the Constitution.
- c) The alteration is put into force immediately after approval by the General Assembly and registration of the new Constitution with the relevant legal authorities.

Application of the Income and Property

- a) The income and property of the Alliance shall be applied solely towards the promotion of the Alliance Objectives.
- b) An Alliance member may pay out of, or be reimbursed from, the property of the Alliance reasonable expenses properly incurred by him or her when acting on behalf of the Alliance.
- c) None of the income or property of the Alliance may be paid or transferred directly or indirectly by way of dividend bonus or otherwise by way of profit to any member of the Alliance.
- d) This does not prevent:
 - 1) A member who is not also an Alliance member from receiving reasonable and proper remuneration for any goods or services supplied to the Alliance;
 - 2) An Alliance member from buying goods or services from the Alliance upon the same terms as other members or members of the public;
 - 3) The purchase of indemnity insurance for the Alliance members against any liability that by virtue of any rule of law would otherwise attach to an Alliance member or other member in respect of any negligence, default, breach of duty, or breach of trust of which he or she may be guilty in relation to the Alliance but excluding:
 - (i) Fines;
 - (ii) Costs of unsuccessfully defending criminal prosecutions for offences arising out of the fraud, dishonesty or wilful or reckless misconduct of the Alliance member or other officer;
 - (iii) Liabilities to the Alliance that result from conduct that the Alliance member or other officer knew or ought to have known was not in the best interests of the Alliance or in respect of which the person concerned did not care whether that conduct was in the best interests of the Alliance or not.
- e) No Alliance member may be paid or receive any other benefit for being an Alliance member.

Dissolution of the Alliance

- 1) The voluntary dissolution of EMEA can only be decided based on a request in writing to the EMEA Executive Committee from three-fourths of the Alliance members. It must be decided in an extraordinary General Meeting convened only for this purpose and receive a vote by a two-third majority of those present who are entitled to vote.

- 2) The final EMEA Executive Committee has to announce the voluntary dissolution of the Alliance in writing.
- 3) If the members, by a two-thirds majority, resolve to dissolve the Alliance, the Alliance members will remain in office as Alliance members and be responsible for winding up the affairs of the Alliance in accordance with this clause.
- 4) The Alliance members must collect in all the assets of the Alliance and must pay, or make provision for, all the liabilities of the Alliance.
- 5) In the case of a voluntary dissolution of the Alliance, the General Meeting shall distribute the existing assets of the Alliance among the full member national associations, who must use the assets towards fulfilling objectives similar to those of the Alliance. The members may also pass a resolution before, or at the same time as the decision to dissolve the Alliance, specifying the manner in which the Alliance members are to distribute the remaining property or assets of the Alliance, and the Alliance members must comply with the resolution if it is consistent with paragraphs above.
- 6) The Alliance members must notify the authority concerned with the registration of the Alliance promptly that the Alliance has been dissolved. If the Alliance members are obliged to send the Alliance's accounts to that authority for the accounting period that ended before its dissolution, they must send to that authority the Alliance's final accounts.

Repair and Insurance

The Alliance members must keep in repair and insure to their full value against fire and other usual risks all the buildings of the Alliance (except those buildings that are required to be kept in repair and insured by a tenant). They must also insure suitably in respect of public liability and employer's liability.

Notices

- a) Any notice required by this constitution to be given to or by any person must be:
 - 1) in writing; or
 - 2) given using electronic communications.
- b) Notice may be given to a member either:
 - 1) personally; or
 - 2) by sending it by post in a prepaid envelope addressed to the member at his or her address; or

- 3) by leaving it at the address of the member; or
 - 4) by giving it using electronic communications to the member's address.
- c) A member present in person at any meeting of the Alliance shall be deemed to have received notice of the meeting and of the purposes for which it was called.
 - d) Proof that an envelope containing a notice was properly addressed, prepaid and posted by registered mail shall be conclusive evidence that the notice was given.
 - e) Proof that a notice contained in an electronic communication was properly addressed and sent shall be conclusive evidence that the notice was given.

A notice shall be deemed to be given 48 hours after the envelope containing it was posted or, in the case of an electronic communication, 48 hours after it was sent.

Minutes

The Alliance members must keep minutes of all:

- a) appointments of positions and Alliance members made by the Alliance members
- b) proceedings at meetings of the Alliance
- c) meetings of the Alliance members and EMEA Executive Committees of Alliance members including the following:

Annual Report and Return and Accounts

The Alliance members must comply with their obligations under the authority at which it is formally registered with regard to:

- a) the keeping of accounting records for the Alliance;
- b) the preparation of annual statements of account for the Alliance;
- c) the transmission of the statements of account to the Alliance;
- d) the preparation of an annual report and its transmission to the regulating authority
- e) the preparation of an annual return and its transmission to the regulating authority



Accounts must be prepared in accordance with the provisions of any statement of recommended practice issued by the regulating authority, unless the Alliance members are required to prepare accounts in accordance with the provisions of such a statement prepared by another body.

Dispute resolution and effectiveness

This Constitution shall be governed by and construed in accordance with the laws of the Alliance's country of domicile. The exclusive place of jurisdiction for all disputes arising in connection with, or based on, this Constitution shall be the domicile location of the Alliance.