

The image features a stylized map of Europe in a vibrant blue color, set against a dark background with radiating light beams. Above the map, the acronym 'EMEA' is displayed in large, bold, white capital letters. Surrounding the text and map are twelve golden-yellow stars, arranged in a semi-circular pattern reminiscent of the European Union flag. The overall composition is dynamic and modern.

EMEA

**CONSTITUTION OF THE EUROPEAN ME
ALLIANCE**

Constitution of the European ME Alliance

Adoption 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 and in this document it is called EMEA).
The abbreviation for the alliance is EMEA.
- b) The association has its headquarters at

**EMEA
Dorp 73
3221 Nieuwrode
Belgium**

with local offices in Belgium, Denmark, Finland, France, Germany, Iceland, Holland, Ireland, Italy, Norway, Spain, Sweden, Switzerland and UK - and other countries as the membership increases.

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

Alliance Purpose

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 European ME Alliance (EMEA) aims to –

- Establish correct recognition of myalgic encephalomyelitis as an organic illness requiring biomedical research to treat and cure
- Establish correct diagnosis of patients
- Establish specialised biomedical centres for education/treatment/cures

The Alliance will help collectively progress the understanding, perception and treatment of Myalgic Encephalomyelitis, by establishing this Alliance Myalgic Encephalomyelitis gets the recognition it deserves across Europe as an illness in its own right.

Objects of the Alliance

- a) The Alliance is non-commercial, politically independent and non denominational.
- b) The Alliance is non-profit making, its activities extend to the member countries.
- c) The purpose of the Alliance is to gather and disseminate information about Myalgic Encephalomyelitis through EMEA to establish contacts and make suggestions how to heighten awareness of myalgic encephalomyelitis among the public, the business community, the professions and politicians.
- e) One of the Alliance aims will be to forge links between the medical profession and research institutes working with Myalgic Encephalomyelitis in the individual member countries and all of Europe.

Member organisations of EMEA have agreed the following principles –

Members of the European ME Alliance endorse the principles of the 2003 Canadian Consensus Document for Diagnosis and Treatment for ME/CFS.

Members of the European ME Alliance endorse the principles of the 2006 paediatric definition from Dr Leonard Jason et al.

Members of the European ME Alliance promote the fact that ME (myalgic encephalomyelitis) is a neurological illness and listed at G93.3 of the World Health Organisation Index of ICD-10.

Members of the European ME Alliance understand the necessity to use the composite term ME/CFS at the moment for ease of reference/standardisation.

Members of the European ME Alliance support biomedical research into establishing sub groups of ME/CFS which will lead to treatments and cures for this illness.

The European ME Alliance has, as an objective, the preparation and promotion of a common set of documentation, in all languages, for Alliance use that is supplemented by local information.

Membership

Membership is open to organisations who are interested in furthering the objects which are approved by the Alliance members.

The Alliance members are: -

- 1) Full Members
- 2) Associate Members
- 3) Sponsoring Members
- 4) Honorary Members

- a) Full members are representatives of a national ME support group of any European Country. The full member will be the originating member for any country. The full member will have voting rights in the decision-making forums held by EMEA.
- b) 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 other meetings organized by EMEA.
- c) 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.
- d) Honorary members can be persons who have earned especial merit in furthering the aims of the association; they become members after the approval of the EMEA General Meeting. They will be nominated by the EMEA Committee or the EMEA General Meeting.
- e) The members decide at a member's meeting, by a 2/3 majority, who shall become a member. The EMEA voting rules apply. Membership can only be refused with reason. This decision will be notified to the candidate member. Appeal against this decision is possible and has to be addressed to the General Meeting within one month after notification. The General Meeting decides with a two-thirds majority required, whether or not the candidate becomes a member.
- f) No-one may be elected as an Alliance member or an Officer at any annual general meeting unless prior to the meeting the Alliance is given a notice that:
 - 1) is signed by a member entitled to vote at the meeting;
 - 2) states the member's intention to propose the appointment of a group as an Alliance member;
 - 3) is signed by the group/individual nominee that is to be proposed to show their willingness to be appointed.
- g) Membership is not transferable to any other group.
- h) All Alliance members shall sign the Alliance Principles and agree to the constitution.

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.
- d) Associate, sponsoring and honorary members have only a seat at meetings.
- e) Currently there are no membership fees for membership of EMEA. This may change in the future as agreed by full members.
- f) All members are obliged to abide the constitution of the Alliance and the decisions of the General Meeting.
- g) All members are expected to treat all matters discussed within EMEA activities as confidential. Failure to do so could lead to termination of membership as agreed in an EMEA meeting.

Termination of membership

- a) Membership will be terminated by:
 - Resignation
 - Expulsion
 - Dissolution of legal entities
 - Cancellation of membership
- b) Resignation is possible at any time giving written notice to the committee. Resignation does not exclude the obligation concerning the membership of the Alliance ongoing year.
- c) Expulsion from the Alliance is effected by unanimous decisions of the full committee and is only permissible for grave reasons, such as not abiding by the constitution of the Alliance or any other written rules approved by 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 General Meeting within one month after notification. At the General Meeting the member has the right to defend themselves. The General Meeting may decide, with two-thirds majority, that the member may continue the membership. During the time from notification till the decision of the general Meeting the membership of the member will be suspended.
- d) Cancellation from the Alliance will be effected by unanimous majority decision of the full committee. Cancelling is only permissible if the member is not able to fulfill the obligations as a member and is not able to pay its annual memberships fee. Cancelling will take effect at the time the decision is notified to the member. An appeal is permissible.
- e) If a member group ceases to exist then that group's membership of the alliance will be terminated.

Chair

- a) General meetings shall be chaired by the person who has been elected as Chair.
- b) If there is no such person or he or she 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 present and willing to chair the meeting within fifteen minutes after the time appointed for holding it 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.

Executive Committee

- a) The Alliance and its property shall be managed and administered by an Executive committee (hereafter referred to as "the Executive committee" comprising the Alliance members elected in accordance with this constitution. The Executive committee members shall be full Alliance members of the Alliance.
- b) The Executive committee shall consist of the following:
 - The Chairman
 - The Secretary
 - The Treasurer
 - At least one other Alliance member
- c) The committee members are elected by the General Meeting for a period of two years and may be re-elected as agreed at the General Meeting.
- d) An Executive committee member must be a full member of the Alliance.
- f) The first Alliance members and the Executive committee members shall be those persons elected as Alliance members and Executive committee members at the meeting at which this constitution is adopted.
- g) The Executive committee will conduct the day to day running of the Alliance.
- h) The Executive committee is qualified to invite advisory members.
- i) Executive committee meetings shall be convened at least 3 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. Meetings shall be notified, stating the agenda and all papers involving the agenda. The secretary sends the notification, after consulting the president, at least six weeks before the meeting is scheduled to take place.
- f) The minimum committee will be the president or Vice-president plus two other members.
- g) the composition of the committee has to be representative regarding the composition of the full members in the General Meeting.
- j) The committee is competent to fulfill all tasks as results of the management of the Alliance so far as it does not belong to the task of the General Meeting.
- k) If for one reason the committee consists of less than five members, the Executive committee is obliged to convene a General Meeting. During this period the committee is competent to settle current affairs.
- m) The Executive committee is obliged to hold a record of all members.
- n) The Executive committee is obliged to make minutes of all committee meetings.

General Meetings.

- a) The Alliance must hold a 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 5 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 Alliance members fail 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 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 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 5 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 present, the 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 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 besides those who are given by law or constitution of the Alliance to the 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) Extraordinary General Meetings may be convened when required and must be convened at the request of at least a quarter of the members. The notification shall state the agenda
- s) Duties of the General Meeting:
 - Election and Discharge of committee members
 - Election and Discharge of Auditors Delivery of Committee's Activity Report
 - Delivery of Financial Report Budget for the next year including the membership fee
 - Resolution on changes of the constitution
- t) The General Meeting will be presided by the Chairman 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 documentation, acceptance of documentation of a principle nature requires a two-thirds majority.
- v) Every full member has one vote. Proxies may be appointed in writing which has to be produced to the president before the General Meeting commences.
- w) The 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 unless it could properly have been conducted at the meeting had the adjournment not taken place.
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.

Votes

- a) Each full member shall have one vote but 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.
- b) Since the nature of the illness (ME/CFS) means that some members may be unable to attend the Meetings, the Management Committee may arrange postal ballots and/or proxy voting to enable full participation in vital decision making.

Powers of Alliance members

- a) The Alliance members must manage the business of the Alliance and they have the following powers in order to further the Objects (but not for any other purpose):
- b) To raise funds. In doing so, the Alliance members must not undertake any substantial permanent trading activity and must comply with any relevant statutory regulations;
- c) to co-operate with other voluntary bodies and statutory authorities and to exchange information and advice with them;
- d) to establish or support any charitable trusts, associations or institutions formed for any of the purposes included in the Objects;
- e) to obtain and pay for such goods and services as are necessary for carrying out the work of the Alliance;
- f) to open and operate such bank and other accounts as the Alliance members consider necessary (all cheques must be signed by two Alliance members).
- g) 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;
- h) In financial matters the Alliance will be represented by the Chairman and the Treasurer. If they are not able to act, they can authorise other committee members.
- i) to do all such other lawful things as are necessary for the achievement of the Objects;
- j) No alteration of this constitution or any special resolution shall have retrospective effect to invalidate any prior act of the Alliance members.
- k) 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 .
- l) 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.
- m) To encourage and support further research into ME/CFS and to disseminate to the public.
- n) To raise funds to support the activities of the Alliance and research into ME/CFS.

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 consider whether the nominee has been properly appointed by the 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 by any other organisation on a National or European level
- d) Gifts, legacy or testamentary disposition
- e) Any other means
- f) The membership fees have to be laid down in the General meeting and have to be approved.
- g) The membership fees will be paid in Euros.

Auditors

Auditors are elected by the General Meeting for a period of two years. Before a General Meeting one of the auditors shall inspect all the accounts and report thereon to the 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 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.
- c) The alteration is put into force after legalisation.

Application of the Income and Property.

- a) The income and property of the Alliance shall be applied solely towards the promotion of the Objects.
- 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 a 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 willful 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 resolved in an extraordinary General Meeting convened for only this purpose and by a two- third majority of those present who are entitled to vote.
- 2) The final committee has to announce the voluntary dissolution of the Alliance in writing.
- 3) In the case of a voluntary dissolution the General Meeting shall distribute the existing assets of the Alliance among the full member national associations.
- 4) 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.
- 5) 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.
- 6) The Alliance members must apply any remaining property or money:
 - (a) directly for the Objects;
 - (b) by transfer to any Alliance or charities for purposes the same as or similar to the Alliance;
- 7) The members may pass a resolution before or at the same time as the resolution to dissolve the Alliance specifying the manner in which the Alliance members are to apply the remaining property or assets of the Alliance and the Alliance members must comply with the resolution if it is consistent with paragraphs above.
- 8) 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 which 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:
 - (a) in writing; or
 - (b) given using electronic communications.
- b) Notice may be given to a member either:
 - (a) personally; or
 - (b) by sending it by post in a prepaid envelope addressed to the member at his or her address; or
 - (c) by leaving it at the address of the member; or
 - (d) 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 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 committees of Alliance members including:

Annual Report and Return and Accounts.

(1) 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.

EMEA STATEMENT

Myalgic Encephalomyelitis is defined by the World Health Organisation as a neurological illness (code WHO-ICD-10-G93.3). ME is a common illness with a prevalence of 0.4% of the population and with many of the sufferers being children. ME is estimated to cost European economies billions of Euros every year.

No public funding of biomedical research is currently taking place in Europe so biomedical research projects are funded solely by the individual grant applications from researchers and from ME support groups and individuals.

ME is a multi-system illness and distinct sub groups have been identified and some treatments have been shown to be effective. To establish more comprehensive treatments and cures for these and other sub groups requires investment in biomedical research.

The varying symptoms experienced by many severe ME sufferers may include: - post-exertional malaise, general chronic weakness of limbs, neurological disturbances, cognitive problems such as memory loss & concentration difficulties, problems with balance and fine motor control, muscle pain, malaise, hypersensitivity, sleep & temperature disturbance, cardiovascular symptoms, digestive disturbances, visual problems, vocal/muscular limitations.

In the UK ME is five times more prevalent than HIV/AIDS.

25% of people diagnosed with ME may be severely affected – house-bound, often bed-bound, left with little help from the medical community, often made to struggle to obtain benefits and left to an uncertain and debilitating future.

With little funding of biomedical research into ME within Europe we are hoping to attract more support for research activities and hope to convince governments of the need to recognize the need for a European biomedical research strategy to cure this illness.

ME needs more awareness from the public, politicians and healthcare staff. It is a major cause for long term absence from school.

We invite other organisations across Europe to support our objectives to change the perception of this illness and force change in government policies and accept the urgent need for biomedical research into the illness in order to establish treatments and cures for this devastating illness.