

## **E.F.A.P.H**

### **European Federation of Associations of Patients with Haemochromatosis**

**(F.E.A.M.H : Fédération Européenne des Associations de Malades  
de l'Hémochromatose)**

#### **I. Objectives and composition of the federating Association**

##### **Article 1: Formation – Name - Duration – Headquarters**

The federating Association bearing the name of the “European Federation of Associations of Patients with Haemochromatosis”, designated hereafter as the “Federation”, was established on 11th September 2004 and is governed by the law of July 1st, 1901 (France), and by its statutes.

The Federation is formed between those European Haemochromatosis Associations, which adhere to the present statutes. The Federation includes individual members who also adhere to the present statutes. Its aim is not only to federate all Associations concerned with Haemochromatosis through their practical initiatives (prevention, screening, training and informing members and the public at large), but also to heighten public awareness (notably amongst public services and authorities, as well as health professionals) of the genetic Haemochromatosis condition.

The Federation will exist for an unlimited period. Its headquarters are located at 4, rue Paul Demange, Croissy-sur-Seine (78290), in the Yvelines département, France. The headquarters may be relocated by simple decision of the Board.

##### **Article 2: Purpose**

The Federation's means of action are practical field initiatives such as prevention, screening, training and informing members, the public at large, health professionals and the relevant authorities. To achieve this, the Federation assigns individuals and legal entities to represent its interests with various international, national and regional health authorities, public and private hospital, medical and administrative services, wherever its presence is useful. It also informs all its members and the public at large, by any means at its disposal.

##### **Article 3: Members - Dues**

The Federation is composed of associations legally registered in their country of origin, or by duly appointed delegations, whose objectives are compatible with article 1 of the present Statutes. It includes individual members who also adhere to the present statutes. No justification is required for denied membership.

The founding Associations are:

- A.H.O: Association Hémochromatose Ouest “Bretagne - Pays de Loire.”
- A.E.H: Asociacion Española de Hémocromatosis
- A.H.B: Association Hémochromatose Belgique

Requests for new membership are subject to the approval of the Federation's Executive Committee by vote, in compliance with article 1 of these Statutes. All member Associations must be certain their decision complies with their respective statutes, and must have obtained the consent either of their own Board or during their General Assembly. They must provide the Federation's Executive Committee with proof of this consent.

Each member Association designates an officially appointed representative duly authorized to vote on its behalf. A deputy representative must also be appointed to ensure continuity if the official representative is unable to fulfil his or her function.

Each member Association will pay the annual dues fixed by the previous General Assembly. The member Association must be up-to-date with its dues for its representative to exercise its right to vote at the General Assembly.

Honorary membership can be attributed by the Board to people for the signal services they render or have rendered to the Federation. Moreover, Honorary founder membership is attributed, under the same conditions, to members who were involved in setting up the Federation. The Executive Committee must approve individual memberships. Each year, the General Assembly fixes the dues to be paid by individual members. Honorary members may be exempted from paying their annual dues.

#### **Article 4: Termination of membership**

Membership of an Association or of an individual member can be terminated by:

- 1) Resignation, decided in accordance with the statutes of the concerned Association by its General Assembly or its Board.
- 2) Dissolution of this member Association, or any substantial amendment of its statutes, resulting in the loss of compliance with article 1 of the Federation's Statutes.
- 3) At an individual member's initiative by sending a simple letter or e-mail, or in the event of death.
- 4) Expulsion decided by the Federation's Board, pursuant to a member's repeated absences, non-payment of its dues, or for any other serious motive.

A registered letter previously invites the member concerned to submit his or her defence to the President of the Federation or to his or her duly mandated representative.

## **II. Administration and operations:**

#### **Article 5: Composition of the Board – Co-opting**

The Federation is administered by the Board comprised of the number of members decided by resolution at the General Assembly and consisting of at least 3 members and at most 11 members amongst members of the Federation.

Each Association Board member is represented by any authorized individual person for whom the Federation has received prior notification. The members of the Board, hereafter designated as the "Administrators", are elected by secret ballot for 2 years by the General Assembly and chosen among the various member categories that comprise this Assembly. Outgoing members may be re-elected. In the event of a vacancy, the Board provides for the temporary replacement of the Administrator, and the permanent replacement will be voted upon at the following General Assembly.

Each Administrator may be represented by another Administrator, however each attending Administrator can only represent one other Administrator.



If the number of candidates is inferior or equal to the maximum authorised number of Administrators to be elected, excluding Honorary Founding Members, the General Assembly will then endorse the election of all candidates without having to proceed with a vote.

To elect Board members, each member of the Federation will indicate on its ballot paper its choice amongst the candidate members. At the end of the vote, and within the limit of the maximum number of members to be elected, the candidates who have obtained the majority of votes are elected. In the event of a tied vote, the most senior candidate in terms of age will be elected.

Honorary Members attend the Board Meetings, participate in the debates, but do not have the right to vote. The Federation's Honorary Founder Members are automatically members of the Board and dispose of the same rights as all other members of the Board.

#### **Article 6: Authority of the Board - Deliberations – Minutes**

The Board is responsible for managing the Federation, notably to define its policies and general orientations and to ensure the efficient functioning of the Federation. The Board informs the General Assembly of its decisions and initiatives.

The Board meets at least once a year, or whenever its President invites the Administrators to meet, or upon the request of a quarter of the Federation's members. At least one third of the members of the Board are required to attend to validate decisions. Decisions shall be taken on the basis of the simple majority of members present or represented. In the event of a majority not being achieved, the President has the casting vote.

Minutes will be drawn up for each session. The President and the Secretary-General will sign these minutes. They will be drawn up on numbered pages, with no blanks or deletions, and kept at the Federation's Headquarters. As the Federation's working language is English, minutes will be written in English and translated by members or their delegate into their respective languages for their internal communication. These minutes will be rendered in French for the purpose of /and made available to the French Authorities.

#### **Article 7: The Board's Executive Committee**

The Board elects an Executive Committee from amongst its members, composed of at least one President, a Secretary-General, a Treasurer and possibly one or several Vice-Presidents, and, when possible, a deputy for each position in order to ensure continuity in the event of absence/impediment. The Executive Committee is elected for 2 years, coinciding with the Board's mandate. The outgoing President statutorily becomes Vice-President and hence a member of the Board.

The Board can decide to create various Committees to study and advise on matters the Board or its President requests, and to carry out any arising actions. The Board appoints the members of these Committees.

The Executive Committee implements decisions taken by the Board. It handles day-to-day matters, proposes actions and projects, prepares the Budget and reports to the Board.

The President represents the Federation for all civil actions and is vested with all powers to this effect; he presents or lets the General Secretary present the annual report to the General Assembly. The Secretary-General is responsible for convening members of the Board, of the Executive Committee and of the General Assembly, for which minutes will be taken; the

Secretary-General keeps the ledgers required by article 5 of the revised French Associations Act of 1<sup>st</sup> July 1901; he discharges all the formalities due to the French administration. The Treasurer keeps the books or supervises the Federation's bookkeeping as well as the preparation of the Federation's Budget; he is responsible for collecting and receiving the members' financial contribution. The President delegates under his control to the Treasurer the payment and collection of all sums due. The Treasurer establishes an annual report of the Federation's finances and presents it at the General Assembly.

The Executive Committee meets at least twice a year, including at the statutory General Assembly, either physically or by any other means of communication (telephone conference or on line, videoconference, etc.). The presence of half of all members of the Executive Committee or their representatives is required to validate its decisions. Decisions are taken by majority voting of the Executive Committee members present or represented, and in the event of equal votes, the President has the casting vote.

Minutes of the meetings must be approved by the Executive Committee at the following meeting and signed by the President and the Secretary-General. They will be drawn up on numbered pages with no blanks or deletions and are kept at the Federation's headquarters.

In the event of non-attendance to three consecutive Executive Committee meetings with no excuse provided, the absent member may be considered as having resigned if proposed by the President or the Secretary-General.

#### **Article 8: Remuneration of Board and Executive Committee members**

Members of the Board and of the Executive Committee will receive no remuneration for the functions they are entrusted with.

Only expenses will be reimbursed to all members of the Association (and/or their delegates) upon presentation of supporting justification and/or receipts. These reimbursements must be authorised by the President and/or the Treasurer once the request is submitted accompanied by the relevant receipts, which may be the object of verification.

Salaried persons paid by the Federation can be called upon by the President to attend, on a consultative basis, the General Assembly and Board meetings.

#### **Article 9: General Assembly**

The Federation's General Assembly is comprised of a duly appointed representative of each member Association, as stipulated by the statutes of each of the Federation's member Associations. It is also comprised of individual members. At least one third of duly appointed representatives of member Associations is required to validate decisions.

The General Assembly is held once a year and each time it is convened by the Board or upon the request of at least one quarter of the members of the Federation. Its agenda and venue are established by the Board on proposal from the Executive Committee. Notification to attend is sent by regular post or by e-mail at least fifteen days before the General Assembly. The latter selects its committee, which may be the Executive Committee. It is informed of and approves the Board's annual management report, concerning the Federation's financial and legal status.

The General Assembly reviews and approves the Board activities report, the accounts for the past financial year, votes the budget for the following financial year, deliberates over questions on the agenda, and, if required, provides for the replacement of members of the Board. The accounting year corresponds to the calendar year, unless the Executive Committee proposes a change to the Board.



General Assembly meetings are not subject to confidentiality or secrecy and can be attended by guests and/or observers who may be invited by members who are up to date with their dues by the day on which the General Assembly is held. In such circumstances, guests and/or observers have no right to vote, do not participate in voting on resolutions contained in the agenda, and can only express themselves publicly when invited to do so by the designated Chairman of the meeting.

Only duly appointed representatives of member Associations, honorary founding members and individual members, who are up to date with their dues on the day of the Assembly, can vote. Via their legally appointed representative, member Associations have five votes each. All other members have only one vote. Decisions are adopted by simple majority of the attending and represented members; in the event of equal votes, the Chairman has the casting vote. Each member attending may only accept 2 proxies over and above his or her own vote.

Minutes will be drafted of the meetings. These minutes are signed by the Chairman and the Secretary. They are drawn up on numbered pages with no blanks or deletions and are kept at the Association's headquarters.

The annual report and accounts are provided to all members of the Federation each year.

Unless the measures stipulated in the 3<sup>rd</sup> paragraph of article 8 of the present statutes are applied, persons salaried by the Federation are not members and will not attend the General Assembly.

#### **Article 10: The President's authority**

The President of Federation represents the Association in all civil matters. The President authorises expenditures. However, it is agreed that the President can delegate authorisation for expenditures to the Treasurer who will then inform the President and the Secretary-General.

In the event of legal representation, the President can only be replaced by a representative to whom he has given special power of attorney.

The Federation's representatives must be in full possession of their civil rights.

#### **Article 11: Board decisions must be approved by the General Assembly**

Decisions taken by the Board concerning the acquisition, exchange and disposal of property required to meet the Federation's objectives, as well as mortgages for the aforementioned property, leases exceeding nine years, disposal of property contained in an endowment fund, as well as in loans, must all be approved by the General Assembly.

#### **Article 12: Specific deliberations**

Decisions by the Board to accept donations and legacies take effect in compliance with the conditions stipulated under article 910 of the French Civil Code.

Decisions taken by the General Assembly concerning the disposal of movables and real estate contained in an endowment fund, taking out mortgages and loans, must be validated by the Administrative authorities.

### **III. Annual resources**

#### **Article 13: Annual resources**

The annual funding of the Association is derived from:

- 1) Dues and subscriptions paid by its members;
- 2) Subsidies from the state, region, department, municipalities and public or European Union bodies/organisations;
- 3) Proceeds from gifts to be used as decided during the accounting year;
- 4) Financial resources exceptionally derived from, and if required with the assent of the authority concerned, collections, conferences, tombolas, raffles, concerts, dances and performances, patronage, donations, etc., authorised in aid of the Federation;
- 5) Financial resources derived from sales and payment for the provision of services.

#### **Article 14: The Association's accounts**

Under the responsibility of the Treasurer, accounts will be kept showing an annual financial statement, balance sheet and appendix. The Treasurer submits the financial report for approval, initially to the Board then to the General Assembly

The use made of the funds resulting from state/government subsidies granted during the past financial year are justified each year to the Head of the French Departmental Administration ("Préfet du Département"), Ministry of the Interior and Ministry of Health.

### **IV. Amendment of the Statutes and Dissolution**

#### **Article 15: Amendments to the Statutes**

The Statutes may be amended by the General Assembly when proposed by the Board or by one tenth of the members who make up the General Assembly. In either case, proposals to amend the Statutes will appear on the agenda of the next General Assembly, which must be sent to all members of the Assembly at least 15 days in advance.

At least a quarter of all active members must attend the Assembly. If this quorum is not obtained, a second General Assembly will be held, but not less than fifteen days later, and this time its decisions are considered valid, whatever the number of members present or represented.

In all events, the Statutes can only be amended by a two-thirds majority of the members present or represented.

#### **Article 16: Dissolution**

If the General Assembly is specially convened to decide on the dissolution of the Federation, in compliance with the conditions stipulated in the previous article, this Assembly must be attended by at least half plus one of the active members.

If this quorum is not obtained, a second General Assembly will be held, but not less than fifteen days later, and this time its decisions are considered valid, whatever the number of members present or represented.

In all events, dissolution can only be decided by a two-thirds majority of the members present or represented.

#### **Article 17: Liquidation**

If the Federation is dissolved, the General Assembly will appoint one or several audit commissioners for the liquidation of the Association's assets.



Net assets shall be given to one or more similar public or state-approved organisations, or to organisations mentioned under article 6, paragraph 5, of the revised French Associations Act of 1<sup>st</sup> July 1901.

**Article 18: Official publications**

The General Assembly's resolutions, as stipulated under articles 15, 16 and 17, are immediately sent to the French Minister of the Interior and to the Minister in charge of Health. They are only valid after receiving the Government's approval.

As the Federation's working language is English, the General Assembly's resolutions, as stipulated by articles 15, 16 and 17, will be sent to the French Minister of the Interior and Ministry in charge of Health after being translated into French.

**V. Surveillance and Internal Rules**

**Article 19: Formalities**

The President or the Secretary-General must inform, within three months, the French departmental or sub-departmental administrative centre of the district where the Federation has its headquarters, of any modifications concerning the Federation's administration or management.

The Federation's ledgers, as well as its accounting records, will be presented on site whenever requisitioned by the French Ministry of the Interior or the Departmental Head, directly to the aforementioned or to their delegate or any civil servant they may have accredited.

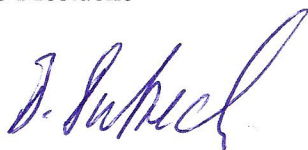
The annual report and accounts are sent each year to the Head of the departmental administration, the Ministry of the Interior and to the Ministry of Health.

**Article 20: Internal Rules**

The Federation may have Internal Rules. In this event they are prepared by the Board and endorsed by the General Assembly before being sent to the Departmental administrative centre ("Préfecture du département"). They cannot come into effect, nor be amended, until they are approved by the French Minister of the Interior.

Statutes signed on December 2, 2015 after endorsement by the General Assembly held on October 17, 2015.

The President



**Dr Barbara BUTZECK**

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The Secretary General



**Dr Françoise COURTOIS**

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