European Idiopathic Pulmonary Fibrosis Federation

Rules of Procedure

Adopted during the first Annual General Assembly on 21 February 2016

Article 1 – Status of the Rules of Procedure

These Rules of Procedure are subordinate to the statutes of the European Idiopathic Pulmonary Fibrosis & Related Disorders Federation (EU-IPFF), an international not-for-profit Federation registered under Belgian law, hereunder referred to as the Federation. In the case of any contradiction between the Rules of Procedure and the statutes of the Federation, the latter shall prevail.

Article 2 – Access to membership

1. Full membership of the EU-IPFF is organisational rather than individual. The criteria for membership are established in article 4 of the statutes. These criteria apply to organisations newly applying for membership.

2. Although several associations from the same country may be eligible to becoming a member of EU-IPFF, particular attention will be paid to their geographical scope (i.e. national rather than regional or local).

3. The following procedures shall be followed, in receiving, considering and approving requests to be included as a full member. The enquirer should provide to the EU-IPFF Executive Board the following information in English:
   a. Their statutes in their official language
   b. The mission and main activities of the organisation
   c. The year of legal registration
   d. A commitment to share the aims and objectives of EU-IPFF
   e. A commitment to pay annual fees on demand
   f. A declaration stating that the candidate organisation:
      i. Has no profit-making purpose
      ii. Is independent from commercial or political interest
      iii. As an important part of its activities, develops, influences and implements policies for the promotion of IPF care and services
   g. A declaration of potential conflict of interests

4. The following procedures shall be followed, in receiving, considering and approving requests to be included as an associated member. The enquirer should provide to the EU-IPFF Executive Board the following information in English:
a. indicate the names of the candidates and/ or the organisation that they represent and include a statement from the candidate about themselves and why they want to join the Federation. Organisations will also be asked to send their statutes in official language.

5. On the basis of a duly completed application, accompanied by the necessary documents, the Executive Board shall determine whether the applicant organisation meets the eligibility criteria and shall decide whether or not to recommend the application for acceptance to the General Assembly.

6. Proposals to admit new members have to be approved by a three quarter majority of present or represented full members of the General Assembly.

7. Proposals to exclude existing full members have to be approved by a three quarter majority of present or represented full members of the General Assembly.

8. Proposals to exclude existing associated members have to be approved by a three quarter majority of present or represented members of the General Assembly.

9. Organisations rejected will not be eligible to reapply for one year from the date that the decision is taken.

Article 3 – Payment of fees

1. The procedures for the fixing and payment of membership fees are established in article 6 of the Statutes.

2. Annual membership fees are payable by all members. The Executive Board can authorize, on a case-by-case basis, to waive or reduce the membership fees for organisations in temporary financial difficulty, upon evidence presented by the concerned member to the Executive Board (last budget).

3. The membership fees are set at the Annual General Assembly. Each member will be billed in June. The annual fee must be paid, at the latest, on the last day of the financial exercise.

4. Organisations that have received a reminder and have not responded by the end of May shall be assumed to have resigned.

Article 4 – Rights of all EU-IPFF members

1. Receive copies of the statutes and of the Rules of Procedure of the Federation,

2. Receive notice of all meetings and relevant documents of the General Assembly, at least four (4) weeks in advance, and be represented at meetings of the General Assembly

3. Be consulted in the preparation of EU-IPFF Policy documents and

4. Participate in any appropriate work streams or training sessions.

5. Associated members can present petitions, provide consultative advice, etc

Article 5 – Obligations of EU-IPFF full members

1. The primary obligation of members is to participate actively in the Federation’s activities and pay their membership fees.
2. Member organisations shall notify one named individual to the Executive Board as its nominated representative. This individual shall be the contact person with EU-IPFF and representative at EU-IPFF meetings. When possible, the organisation should also provide the contact details of a substitute from the same organisation who can replace the appointed person.

3. The representative of a member organisation has the obligation to respect the confidentiality of internal EU-IPFF documents.

**Article 6 – Organisational structure**

1. The General Assembly is established as EU-IPFF’s governing body (article 9 of the Statutes), with day-to-day management responsibility entrusted to a Executive Board comprising a minimum of 3 members and a maximum of 7 members (art. 9 of the Statutes). Executive Board members must be Board members of the member organisations they represent.

2. The Executive Board is responsible for appointing three special positions: President, Secretary and Treasurer.

3. The Executive Board is authorised to delegate the daily management of EU-IPFF, with powers to sign on behalf of the Federation, to the President. It has the power to set-up subcommittees or work streams of the Federation.

4. The Executive Board may decide to hire resources or an external provider to conduct Secretariat activities on behalf of the Federation. The decision shall be previously agreed upon by the General Assembly, and foreseen in the Federation’s budget.

5. The administrative Secretariat of the Federation supports the Executive Board in the daily management of the Federation, including the organization of and regular contact with the General Assembly. The administrative Secretariat reports to the Secretary. The Secretariat, by supporting the implementation of the Federation’s workplan, facilitates collaboration between Board members and ensures the continuity of the Federation’s activities.

**Article 7 – General Assembly**

1. The General Assembly has the most extended powers of decision-making in the Federation. The Executive Board is responsible before the General Assembly and regularly reports on progress made in the implementation of the Federation’s annual workplan and objectives.

2. The decision-making procedures, including the quorum and voting system, are laid out in Article 9 of the Statutes.

3. A full member can, exceptionally (upon previous written notification to the President, two weeks prior to the meeting) appoint someone from their own national organization to replace them at a General Assembly meeting.

4. A full member may, on an exceptional basis, be represented at the General Assembly by another full member by means of a proxy, with a clear voting line. No full member can hold more than one proxy.

5. Full members may also exceptionally be able to cast electronic votes BEFORE a General Assembly meeting, on agenda items, if they notified their absence in writing to the President two weeks before the meeting.
6. Associated members are invited to the General Assembly. However, this does not prevent the possibility to organise sessions during the General Assembly for full members only.

**Article 8 - Elections to the Executive Board**

1. Members of the Executive Board are elected at the Annual General Assembly for a term of two (2) years maximum, renewable without limitation, according to the following procedure:
   a. in the first year of establishment, the Secretary and half of the Board will serve the mandate for the exceptional duration of three (3) years in order to establish an alternating system within the Board. The President, the Treasurer and the rest of the Board will serve the standard 2 year mandate.
   b. a preliminary notice of the meeting, giving the proposed date and venue shall be sent to member organisations 4 weeks in advance.
   c. in this preliminary notice, the EU-IPFF Executive Board shall indicate whether any (and, if so, how many) vacancies are to be filled on the Executive Board.
   d. a representative of any full member organisation may be nominated for election to the Executive Board, provided that the organisation's membership dues are fully paid at the time of nomination.
   e. nominations for election to the Executive Board must be received by the General Assembly at least 4 weeks prior to the Annual General Assembly.
   f. the calling notice and final agenda for the meeting shall indicate the names of the candidates and the organisations that they represent and include a statement from the candidate about themselves and why they wish to stand. This information shall be sent one week prior to the General Assembly meeting.
   g. in the event that there are insufficient candidates nominated by the due date to fill the vacant place(s), the President may accept further verbal nominations at the meeting: this discretion may not be exercised if sufficient names have been received by the notified closing date.
   h. In the event that there are no candidates, the oldest member of the Federation is automatically appointed President in the interim.
   i. in the event that any member of the Executive Board resigns during his or her period in office, the Executive Board can replace him/her in the course of a financial year by co-optation. The Executive Board shall seek to co-opt an individual from the member organisation represented by the outgoing Executive Board member. The co-opted member will serve until the next General Assembly. Executive Board members can be removed from office by the General Assembly at any time.

**Article 9 - The role of the Executive Board**

General rules:

1. The Executive Board has the most extended powers of policy, management and administration of the Federation.
2. As indicated in article 10 of the Statutes, no more than 1 representative per country can be elected in the Executive Board.

3. Only full members can be elected in the Executive Board.

4. Executive Board members are elected for a period of two (2) years renewable without limitation. They can be removed from office by the General Assembly at any time. The Executive Board appoints a President, a Secretary and a Treasurer, amongst its members.

5. The President, Secretary and the Treasurer are appointed for a period of two (2) years. This period may be extended only once for a period of two (2) years for the President.

6. Board members collaborate closely to ensure projects are completed, and to guarantee the continuity of the Federation’s activities.

7. The Executive Board must implement the programme of the Annual Workplan, and the provisional budget.

8. Executive Board members can substitute themselves at meetings of the Executive Board by a substitute from their organisations. The names of the substitutes must be communicated to the President of the Board two weeks before a Board meeting.

9. Substitution should be exceptional, e.g. because of health problems.

10. Executive Board members are free to resign at any time by providing written communication to all members and must resign if leaving the member organisation that they represent. In case of resignation before the end of the Executive Board’s mandate, the full member can appoint a replacement to fulfill the vacancy.

11. In case of no indication from the full member on a substitute, the Executive Board can replace a Board seat that falls vacant in the course of a financial year until the next General Assembly.

Executive Board Meeting Procedures:

12. The Executive Board meets in person at least once a year. The Executive Board meets on special convocation of the President or the Secretary. Such convocations are sent by e-mail or letter to all Board members, at the same time. The draft agenda is circulated at least four (4) weeks in advance of meetings to all members. A final agenda and all relevant document are forwarded one (1) week before the meeting.

13. Each member has one vote. Decisions of the Executive Board are taken by a simple majority of the present or represented Executive Board members. The vote of the President is decisive, in case of a tie vote.

14. The Executive Board cannot take any decisions related to the day-to-day management of the Federation unless at least half of its members are present.

15. An Executive Board member can, exceptionally (upon previous written notification to the President, two weeks prior to the meeting) appoint someone from their own national organization to replace them at a meeting.

16. A member of the Executive Board may, on an exceptional basis, be represented by another full member by means of a proxy, with a clear voting line. No full member can hold more than one proxy.

17. Board members may also exceptionally be able to cast electronic votes before the meeting if they notified their absence in writing to the President two weeks before the meeting.

18. The President can invite other people to attend a meeting of the Executive Board. If one or more members of the Executive Board object to the presence of these people, the Executive
Board takes precedence. The Secretary will prepare the Minutes which will be circulated to the Executive Board members within two (2) weeks. After agreement, the Minutes will be circulated to all members within four (4) weeks.

19. The Executive Board may also hold virtual meetings and reach decisions using telecommunication technologies, e.g. telephone and e-mails. Telephone or email/internet conferences can be called with short notice by the President or the Secretary by e-mail.

20. The Executive Board may appoint advisors to assist in achieving the aims of the Federation. These special advisors may be healthcare professionals, elected representatives, patients and carers etc. They may be invited to attend Executive Board meetings but have no voting right.

Duties of Executive Board Members include:

21. Act in the general interest of the Federation, taking into account the interests of all parties involved with the Federation, including observing the principles for composition of the Executive Board.

22. Participate actively in strategic planning and review any matters brought to his/her attention, including policy developments and financial matters, as well as specific actions necessary to implement the strategic plan and the provisional budget.

23. Participate actively in the Executive Board meetings.

24. Ensure that the recording of the proceeding of the Executive Board meetings are correct (minutes are sent out to all members within four weeks after Executive Board meetings).


26. If a member of the Executive Board is frequently absent, he/she is approached by the President for an explanation.

27. The Executive Board will periodically review its performance against its responsibilities and objectives to assess its efficacy and identify areas for improvement. Ultimately, the Executive Board is accountable to the General Assembly.

Conflicts of interest:

28. The Executive Board avoids any form and appearance of conflict of interests with EU-IPFF.

29. A member of the Executive Board immediately reports any conflict of interest (or potential one) that has material significance for the Federation and/or for the member of the Executive Board to the President.

30. A member of the Executive Board will not become involved in decision-making in relation to matters where a potential conflict of interest exists, even if it has been reported.

31. If the President has any conflict of interest (or potential one), he/she reports this immediately to the Secretary of the Executive Board. The President provides the Secretary with all relevant information. The Executive Board decides in the absence of that member whether a conflict of interest is involved.

32. Executive Board members will keep confidential all confidential and proprietary information disclosed in connection with the work of the Executive Board and maintain this confidentiality even after the Federation with the Executive Board ceases.

Article 10 - The role of President
The President shall preside at the meetings of the General Assembly and of the Executive Board. The President represents the Federation externally and ensures the liaison with sponsors. In the case of a tie vote, the President’s vote is decisive. The President shall see to it that all orders and resolutions of the Executive Board are carried into effect in close cooperation with the Secretary.

The President of the Executive Board has the following duties:

1. Provide leadership and direction to the Executive Board, and propose any new ideas to the benefit of patients.
2. Drive the establishment of overall long and short term goals, objectives and priorities for the organisation, in collaboration with other Executive Board members and the Secretary and in meeting the needs of the Federation.
3. Address the Annual General Assembly, and describe implemented activities and projects.
4. Chair the Executive Board and its meetings and - in conjunction with the Secretary - set the agenda for Executive Board meetings, ensure that the members of the Executive Board receive in good time all information required for the proper conduct of their tasks, ensure there is sufficient time for the Executive Board to discuss and make decisions.
5. Be the spokesperson for the EU-IPFF to the public at large and represent the organisation to public authorities, including EU institutions, when required.
6. In conjunction with the Executive Board, provide guidance and leadership to all EU-IPFF members.
7. Arrange for the Secretary to chair meetings in his/her absence.
8. Monitor and evaluate the effectiveness of EU-IPFF’s actions and services through a regular review of programmes and services.

Article 11 – The role of Secretary

General rules:

1. The Executive Board may appoint a Secretary.
2. The Executive Board appoints a current member of the Executive Board who has been a member of the Federation for at least a year.

Duties include:

1. Automatically take over as the President in case of his/her resignation, removal or death until a new President is elected by the General Assembly.
2. Assume function of President in the event of his/her prolonged absence or incapacity.
3. Represent EU-IPFF at events on behalf of the President if he/she is not available or if practical circumstances favour it.
4. Chair Executive Board meetings when the President is not available.
5. Perform special duties as agreed by the Executive Board, such as the supervision of the work of the Secretariat. In this case, the Secretary shall be accountable for the work of the Secretariat to the President.
Article 12 – The role of Treasurer

General rules:

1. The Executive Board may appoint a Treasurer who acts as advisor to the Executive Board.
2. The Treasurer shall be familiar with financial administration and have an interest in financial management.

Duties include:

1. Ensure that systems and procedures in respect of financial management of the EU-IPFF and the external accountability are in line with current standards, in terms of accuracy, transparency, timeliness.
2. Appoint and maintain relations with the external auditor also with regard to current standards/legislation applicable to financial accounting by an ivzw (internationale vereniging zonder winstoogmerk).
3. Participate in the development of multi-annual financial plans.
4. Review and advise on annual budgets and draft annual budget/multi-annual financial plans to the General Assembly.
5. Liaise with the Secretary and the administrative Secretariat to develop an audited annual report to be shared with all members (as mentioned in article 11 of the Statutes).

Article 13 - consultation on major policy positions

The main objective of the Federation is the improvement and acceleration of development of new therapies for the treatment of IPF. One of the objective of the EU-IPFF, amongst others, is advocacy and lobbying to influence European policy makers in favour of improved IPF care and services in accordance with article 3 of the statutes. To help in the task of major policy development, the Executive Board may establish expert groups to assist the Federation in developing advocacy materials to this end. All members are entitled to be consulted in the development of such materials.

Article 14 - financial regulations

1. The EU-IPFF raises its funds amongst its members according to decisions made by the General Assembly.
2. The EU-IPFF, represented by the Executive Board, may receive grants, donations and loans from the institutions of the European Union, foundations and commercial companies, provided that it does not affect its independence.
3. The Executive Board shall open bank accounts as are necessary for the good conduct of the EU-IPFF’s business, and shall authorise Board Members to act as signatories on contracts and other documents (grant proposals and agreements), that implicate EU-IPFF in a financial undertaking.
4. The Executive Board shall prepare accounts and budgets for submission to the General Assembly, as required in article 11 of the statutes.
Article 15 - notices

Wherever the statutes or the internal rules refer to notices or documents etc. which need to be distributed to member organisations, this shall mean any of the following means of written communication: letter or e-mail. All members must receive notices, documents etc. by the most appropriate means for them (i.e. email or standard mail).