

# STATUTES OF THE EUROPEAN IDIOPATHIC PULMONARY FIBROSIS & RELATED DISORDERS FEDERATION

The associations listed below

- Action for Pulmonary Fibrosis (APF), with its registered office at Beechcroft, Westley, Bury St Edmonds, Suffolk, IP33 3TR Great Britain, Represented by Karen Hughes, Trustee, 109 Kineton Green Road, Solihull, West Midlands B92 7DT
- AMA - FUORI DAL BUIO, with its registered office at AOU Policlinico di Modena, Via del Pozzo 71, c/o Centro Malattie Rare del Polmone, 41124 Modena, Italy, represented by Rosalba Mele, President, Via del Pozzo 71, c/o Centro Malattie Rare del Polmone, 41124 Modena, Italy.
- Asociación de Familiares y Enfermos de Fibrosis Pulmonar Idiopática (AFEFPPI), with its registered office at Tablas de Daimiel 2 – local 7, 28924 Alcorcón (Madrid), Spain, represented by Carlos Lines Millán, President, Tablas de Daimiel 2 – local 7, 28924 Alcorcón (Madrid), Spain.
- Association Belge contre La Fibrose Pulmonaire Idiopathique (ABFPI), with its registered office at Avenue Reine Astrid 77/9, 1410 Waterloo, Belgium, represented by Michel Faucher Viegas, President, Avenue Reine Astrid 77/9, 1410 Waterloo, Belgium.
- Association Pierre Enjalran Fibrose Pulmonaire Idiopathique (A.P.E.F.P.I), with its registered office at 17, rue de la CAOUE, 31210 – ARDIEGE, France, represented by Françoise Enjalran, President, 17, rue de la CAOUE, 31210 – ARDIEGE, France
- Belgische Vereniging voor Longfibrose vzw (BVL), with its registered office at Jules de Cocklaan 95, B-9050 Gentbrugge, Belgium, represented by Herman Van Lysebeth, Board Member, Wolfshaegen 175A, B-3040 Neerijse, Belgium.
- British Lung Foundation (BLF), with its registered office at 73-75 Goswell Road, London, EC1V 7ER, Great Britain, represented by Ruth Sabella, IPF Project Manager, 73-75 Goswell Road London EC1V 7ER, Great Britain
- Irish Lung Fibrosis Association (ILFA), with its registered office at Lavery House, Earlsfort Terrace Dublin D02 T625, Ireland, represented by Liam Galvin, President, Lavery House, Earlsfort Terrace Dublin D02 T625, Ireland.
- Longfibrose NL, with its registered office at Stationsweg 127, 3800 AP Amersfoort, Netherlands, represented by Lida Naber, Project Manager, Stationsweg 127, 3800 AP Amersfoort, Netherlands.
- Lungenfibrose e. V., with its registered office at Postfach 150208, 45242 Essen, Germany, represented by Dagmar Kauschka, President, Postfach 150208, 45242 Essen, Germany.
- Lungenfibrose Forum Austria with its registered office at Dänekeplatz 5/14, 3052 Innermanzing, Austria; represented by Günther Wanke, President, Dänekeplatz 5/14, 3052 Innermanzing, Austria.

agreed among themselves to set up, in accordance with Belgian law, an international non-profit association and established the statutes thereafter.

## Art. 1 General Principles

The association was established as an international non-profit association and is submitted to the conditions of Title III of the Belgian law of June 27, 1921 concerning non-profit associations, international non-profit associations and foundations (articles 46 to 57).

The association is called *European Idiopathic Pulmonary Fibrosis & Related Disorders Federation*. In contact with third parties the abbreviation *EU-IPFF* can also be used.

All deeds, invoices, announcements, notifications and other documents emanating from the Association mention the name or abbreviation, followed directly by the words 'internationale vereniging zonder winstoogmerk' (international not-for-profit organisation) or the abbreviation 'ivzw' as well as the address of the registered office.

## Art. 2 Registered Office and Working Language

The registered office of the Association is located at *Jules de Cocklaan 95, B-9050 Gentbrugge*.

The registered office can be transferred to any other place in Belgium by decision of the Executive Board, to be published in the Supplements of the *Moniteur Belge/ Belgisch Staatsblad*.

For reasons of practical nature, additional offices can be established at any given moment or in any country in Europe.

The working language of the Association is English. Dutch will be used where this is requested by law.

## Art. 3 Goal of the Association

The Association serves the following social and scientific non-profit aims, of international utility:

- a) Supporting an immediate and sustainable improvement of the quality of life and survival time of IPF patients, and of patients suffering from other interstitial lung diseases, through directly influencing pharmacological and medical research and development, as well as the access to non-pharmacological assistance for patients.
- b) Defending the interests of *IPF* patients at European level with emphasis on:
  - access to treatment and services, including non-pharmacological treatment and medication
  - access to information on new and current trials
  - promotion of research into new treatment/medication
  - information exchange and collaboration between European and international IPF patient associations
  - supporting the establishment of patient associations in countries where no such associations exist

To achieve these goals, the association will undertake the following activities:

- exchanging information and collaborating with relevant European and international organisations and bodies
- involving patients in research activities and studies to improve current treatment options for IPF patients
- representation in relevant European and international organisations

- organisation of symposia, workshops, educational and training events for different stakeholders
- providing information, e.g. via a website
- publishing materials such as leaflets, brochures, books, audio-visual materials, etc.

The association may enter into contracts, purchase, lend or lease, pay salaries to employees other expenses, that are necessary to manage its affairs.

In addition, the association can undertake all activities that are directly or indirectly contribute to the realisation of the aforementioned social and scientific non-profit objectives, including additional commercial and profitable activities that are allowed by law and of which the profits shall always be used for the realisation of the social and scientific, not-for-profit objectives.

#### **Art. 4 Membership criteria**

To be accepted as a full member of the Association, one has to fulfil the following cumulative and minimal criteria:

- Not-for-profit organisation
- Independent organisation
- A key focus on idiopathic pulmonary fibrosis

These membership criteria can be further developed in the Rules of Procedure of the Association.

#### **Art. 5 Types of membership**

The Association is composed of members with and without voting power:

##### *Full members:*

They represent European associations focusing on IPF and allied disorders. They include the founding members and new members that are accepted after a trial period of one year and ratification by the General Assembly by a three quarter majority of present or represented full members. They are subject to the provisions of the statutes and the rules associated with them.

Full members, up-to-date with their membership fee, have the right to participate in meetings of the Association with full voting rights. They share the objectives of the association and are free from political, commercial or government ties.

##### *Associated members:*

Natural or legal persons who subscribe to the objectives of the Association and are accepted by the Board, e.g.:

- Individual patients, with the aim of providing support for the establishment of a national association
- Healthcare professionals specialised in IPF and related disorders
- Other European associations of relevance, e.g. rare diseases, lung health, etc.
- Other non-European pulmonary fibrosis & related disorders associations

They have the right of participation to the General Assemblies but have no voting rights; their rights and obligations are, if necessary, to be set out in the Rules of Procedure of the association.

#### **Art. 6 Membership fee**

Full members pay an annual membership fee. The amount is determined annually by the General Assembly upon proposal by the Executive Board. The fee must have been paid before the last day of the financial exercise.

#### **Art. 7 End of membership**

Any full or associated member may, at any time, resign from the association. The resignation must be notified in writing to the Executive Board. However, each member must fulfil their financial commitments until the end of the financial year.

A membership of full or associated members may be terminated in the following cases:

- a) failure to comply with financial commitments.

Any full or associated member who has failed to pay its membership fees for one year is believed to have terminated its membership. In the event where the member has difficulties in complying with its financial commitments, it may appeal to the Executive Board. The conditions under which its membership in the *EU-IPFF* can be maintained will then be reassessed by the Executive Board. Based on this assessment, the Board will submit a recommendation to the General Assembly, which will decide whether or not to continue the membership.

- b) activities that are detrimental to the European Idiopathic Pulmonary Fibrosis & Related Disorders Federation or violate the association's statutes or Rules of Procedure.

Associated members who undertake activities that are detrimental to the association or in conflict with the rules set out in these statutes and the Rules of Procedure can be excluded from membership by decision of the General Assembly. Any decision on an exclusion of a full member as a result of the undertaking of activities that are detrimental to the association or in conflict with the Statutes of the Rules of Procedure, will be taken at a meeting of the General Assembly by a three quarter majority of present or represented full members. The full member concerned should be notified, at least, sixty days before the meeting and given the opportunity of receiving the relevant evidence against them and defending their actions.

Any renewal of full membership (following an exclusion) will require the support of a majority of three quarter of present or represented members at an Executive Board meeting convened for this purpose. Any such decision will require confirmation by a majority of three quarter of present or represented full members at a subsequent meeting of the General Assembly. The renewal will only enter into force after the aforementioned confirmation by the General Assembly.

Resigning or excluded members and their legal successors may not assert rights on the Association's assets.

#### **Art. 8 Organisation**

The organisation of the association consists of:

- a. A general guiding organ, namely the General Assembly;
- b. An executive organ, namely the Executive Board

#### **Art. 9 General Assembly**

### *1. Powers*

The following exclusive powers can only be executed by the General Assembly:

- a. change the statutes;
- b. appoint and dismiss the board members, the external auditor or if necessary the commissioner;
- c. approve accounts and budgets, propose and approve an annual provisional budget;
- d. define mission of the Board and grant discharge to the Board members, or if necessary to the commissioner;
- e. decide on the voluntary dissolution of the association;
- f. accept and exclude full members;
- g. establish or amend the rules of procedure.

### *2. Composition*

The General Assembly consists of all members. Only full members have the right to vote. Every full member holds one vote. Associated members can attend the General Assembly, however without the right to vote.

### *3. Meetings*

The General Assembly is convened annually by the President. The General Assembly can meet in an Extraordinary General Assembly, at the request of the majority of members of the Executive Board or the General Assembly.

When required and/or if the matter is urgent, full members of the General Assembly can – to the extent permitted by law – take any decisions falling within the competence of the General Assembly through consistent and written means (i.e. without arranging a face-to-face meeting).

### *4. Decision-making*

The General Assembly can only deliberate when one half of the full members are present or represented, unless the statutes explicitly state otherwise. Article 7 of the Rules of Procedure explains the available options for full members to exert the right to vote in case of impediment to attend scheduled meetings.

Decisions are taken by simple majority of present or represented members. The exceptions to this rule are highlighted in these statutes.

Exceptional decisions, i.e. inclusion of a new member, exclusion of a full member or amendment of the statutes, require a three quarter majority of the votes of the present or represented full members.

Deliberations regarding items that are not on the agenda are allowed, on the condition that all members, present or represented, unanimously agree to discuss the new item.

The decisions of the General Assembly will be recorded in a register, signed by a member of the Executive Board and kept at the address of the registered office of the Association. A copy of the register is available to members upon demand.

A brief overview of the decisions will be notified in writing to all members within seven working days after the meeting. The final minutes of the meeting of the General Assembly will be sent to all members in the form of a report within four weeks.

## **Art. 10 Executive Board**

### *1. Powers*

The Executive Board can undertake all activities of an executive nature that are needed or support the realization of the objectives of the association, excluding those activities that fall under the competences of the General Assembly.

### *2. Election and composition*

The members of the Executive Board are elected by the General Assembly by a simple majority for a term of two years. The mandate of a Board member can always be renewed.

The Executive Board is composed of at least three persons, and a maximum of seven persons. The Executive Board elects amongst its members a President, Secretary and Treasurer. The position of President can only be taken up for two consecutive terms of two years each by the same person. The General Assembly confirms by simple majority the appointment for the 3 special positions. If the appointment is not confirmed, the Executive Board will submit a new proposal to the General Assembly.

The President and the Secretary cannot be replaced the same year, except under exceptional circumstances, such as health issue, death or resignation of one of them. At least one of them must safeguard the continuation of current activities.

There can be no more than one representative per full member association elected to the Executive Board.

Should two full member associations be located in the same country and should there be more than one candidate to the Board from the same country, only one of the candidates can be elected.

### *3. Roles and responsibilities*

The association shall be liable for any damage or errors caused by its representatives or acting organs in the fulfillment of its objectives. The members responsible for the day-to-day management bear no personal liability for the commitments of the international non-profit association. They are only responsible for the execution of their assigned duties and for any shortcomings in the management of these duties. Members do not enter into any personal liability for commitments made by the international non-profit association.

The President is the head of the Association and presides over both the General Assembly and the meetings of the Executive Board.

The Secretary shall be Acting President in case of absence of the latter.

The Secretary is responsible for carrying out the instructions of the President and the Executive Board of the Association. Specific tasks can be assigned to paid staff and/ or an external service provider. However, the ultimate responsibility remains with the President.

The Treasurer carries out the duties given by and in accordance with the instructions of the Executive Board.

### *4. Termination, dismissal, discontinuation*

Membership of the Executive Board is terminated by the discontinuation, resignation, or exclusion of the represented member, of by the resignation, removal or expiration of the mandate of the Board member. In case of a vacancy during a mandate, as a result of one of the abovementioned reasons,

the Executive Board can appoint a temporary substitute who finishes the mandate of his/her predecessor.

Members of the Executive Board can be dismissed by the General Assembly which will decide by a majority of three quarter of present or represented members.

All documents concerning the appointment, dismissal or discontinuation of members of the Executive Board, prepared in accordance with the law, will be, in view of their deposition in the legal file, notified to the registry of the commercial court and will, at the expense of the association, be published in the Supplements of the Moniteur Belge/ Belgisch Staatsblad.

#### *5. Decision-making*

The Executive Board must meet at least once a year. Date and venue are to be determined by the President in consultation with the Executive Board.

The Executive Board can only deliberate legitimately when at least the majority of its members is present. Decisions of the Executive Board are taken by simple majority. In case of a tie vote, the vote of the President is decisive. In case of absence of the President, the Secretary – who in this case acts as President - has the decisive vote.

A short overview of decisions taken is communicated in written form to all members within seven working days. Final minutes in the form of a report are circulated to all members within four weeks.

Decisions will be recorded in a register, signed by a member of the Executive Board and kept at the address of the registered office of the association.

#### *6. External representational powers*

The Executive Board is mandated to commit the Association to third parties and represents the Association in proceedings and legal actions.

Without prejudice to the powers of representation of the Executive Board, the Association is committed towards third parties and represented in all its proceedings and legal actions by:

- a. one Board member, operating individually; as well as
- b. every individual who has been mandated for this purpose by the Executive Board.

In legal questions, the association shall always be represented by a lawyer. Pending legal proceedings shall be discussed at the annual meetings of the General Assembly.

#### *7. Advisors*

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

### **Art. 11 Financial Rules**

The financial year of the Association shall be from June 1 to May 31. The first financial year shall be from 15 July 2016 to 31 May 2017.

The Executive Board shall provide an annual written report to the General Assembly. This report should be sent to all members at least six weeks before the General Assembly meets.

The bookkeeping for revenues and expenditures, for the purchase and acquisition of goods for the Association must be available for inspection by the members. The annual accounts must, in accordance with article 51 of the Law of 27 June 1921, be included to the association's file that is kept at the registry of the commercial court.

The General Assembly shall appoint an external auditor or, if the law requires, a commissioner to check the regularity of the accounts.

The Association may accept and make use of all donations, contributions, gifts, grants and legacies that specifically or generally support the aims of the Association.

#### **Art. 12 Meeting invitation and reporting**

Each meeting invitation (e.g. Annual General Assembly, Board meetings) must be provided with a provisional agenda and sent at least four weeks in advance. A final agenda should be sent at least one week before the meeting, together with petitions submitted by associated members.

The report of a meeting must be sent within four weeks to all members. The reports of meetings of the Executive Board should be approved by Board members before being shared with all the Association's members. The decisions of all bodies shall be entered in a register signed by a director and kept by the Secretary that ensures this register is available to the members at the registered office of the association.

#### **Art. 13 Modification of the Statutes**

Subject to the Law of June 27, 1921, proposals for amending the statutes may be submitted by the Executive Board or by at least three full members of the General Assembly, provided that they have fulfilled their financial obligations. Proposals to dissolve the Association can only be submitted by one third of the full members.

The Statutes may be amended at any General Assembly, on the condition that two thirds of the full members is present or represented.

The Executive Board will inform all members at least one month in advance, of the date and venue of the General Assembly, where the amendments will be discussed, and share the text of any amendments proposed.

A decision on amending the Statutes is only valid if a majority of three quarter of votes is reached.

In the absence of the quorum of two thirds of the full members, a new General Assembly will be convened under the same conditions as above and will then adopt a final and valid decision on the proposal, regardless of the number of members attending or represented.

Changes to the statutes will be effective only after approval by the competent authority pursuant to Article 50 §3 of the Law of 27 June, 1921, and after publication in the Annexes to the Moniteur Belge/ Belgisch Staatsblad in accordance with Article 51 § 3 of said Act.

#### **Art. 14 Dissolution of the Association**

The Executive Board determines the method of dissolution and liquidation of the Association that should be presented and approved by the General Assembly through a three quarters majority. Any



remaining funds will be transferred to a European-wide non-profit organisation that supports research in idiopathic pulmonary fibrosis or, in the absence thereof, any non-profit objective to be specified.

#### **Art. 15 Rules of Procedure**

Rules of Procedure have been drawn up to facilitate the day-to-day management and organisation of the Association.

The Rules of Procedure are available to all members and may be amended by simple majority of the votes at the General Assembly.

The Rules of Procedure complement the statutes but cannot contravene or add new articles to the statutes. If there is a contradiction between the Rules of Procedure and the statutes, the statutes shall prevail.

#### **Art. 16 Others**

For anything that is not provided or laid down in these statutes, the conditions laid out in Title III of the Belgian law of June 27, 1921 concerning non-profit associations, international non-profit associations and foundations (articles 46 to 57) will apply.

President: Carlo Lines Millán

Secretary: Liam Galvin

Treasurer: Herman Van Lysebeth

Board member: Dagmar Kauschka

Board member: Gilbert Menou

Board member: Rosalba Mele

These statutes were adopted unanimously at the founding meeting held in Brussels, Belgium on 21 February 2016.

In case of legal dispute, the Dutch version is deemed authentic.

Of this Act are 3 original copies were signed on 15 July 2016 by founders in opening paragraph.

Name and signature of all founders and proxy holders