# ARTICLES OF ASSOCIATION OF THE EUROPEAN PULMONARY FIBROSIS FEDERATION

## Preamble

The European Pulmonary Fibrosis Federation previously named the European Idiopathic Pulmonary Fibrosis & Related Disorders Federation was founded in July 2016 by the following patient organisations who came together to register under Belgium Law a international not for profit organisation.

Action for Pulmonary Fibrosis - United Kingdom AMA - FUORI DAL BUIO, Italy Asociación de Familiares y Enfermos de Fibrosis Pulmonar Idiopática, Spain Association Belge contre La Fibrose Pulmonaire Idiopathique, Belgium Association Pierre Enjalran Fibrose Pulmonaire Idiopathique, France Belgische Vereniging voor Longfibrose vzw, Belgium Asthma and Lung UK, United Kingdom. Irish Lung Fibrosis Association, Ireland Longfibrose NL, Netherlands Lungenfibrose e. V, Germany Lungenfibrose Forum, Austria

## Art. 1 General Principles

The Association is established as an international non-profit association governed by Belgian law in accordance with the Code of Companies and Associations (CCA) of March 29, 2019.

The Association is called *European Pulmonary Fibrosis Federation*. In contact with third parties the abbreviation *EU-PFF* can also be used.

All deeds, invoices, announcements, notifications and other documents emanating from the Association must 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 in the Flemish Region.

The registered office can be transferred to any other place in Belgium by decision of the board of directors, to be published in the Annexes to 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 European Pulmonary Fibrosis Federation uses the WHO definition of Europe.

The working language of the Association is English. Dutch, or other membership state language, will be used where this is required by law. If the latter is the case, an English translation shall be made available, but the original text in the local legal language shall prevail.

## Art. 3 Goal and activities 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 pulmonary fibrosis 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

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assistance for patients.

- b) Defending the interests of pulmonary fibrosis patients within Europe with a focus on
  - access to treatment and services, including non-pharmacological treatment and medication
  - access to information on new and current clinical trials
  - promotion of research into new treatment/medication
  - information exchange and collaboration among European and international pulmonary fibrosis 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 pulmonary fibrosis patients
- representation in and to relevant European and international organisations and authorities.
- organisation of symposia, workshops, educational and training events for different stakeholders
- providing information, for example 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 and 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 relevant focus on pulmonary fibrosis or interstitial lung diseases

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 that have a focus on pulmonary fibrosis 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 meeting by a three-quarter majority of present or represented full members. They are subject to the provisions of the articles of association and the rules associated with them.

Full members, who are 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 professional or medical societies or entities
- Other European associations of relevance, for example rare diseases, lung health, etc.
- Other non-European pulmonary fibrosis and related disorders associations

They may participate in the general meetings but have no voting rights; their rights and obligations are, if necessary, to be set out in the Rules of Procedure of the Association. The Rules of Procedure may also be used to define other more informal types of membership, collaboration or partnerships.

## Art. 6 Membership fee

Full members pay a membership fee. The amount is determined by the general meeting upon proposal by the board of directors. Details on execution and procedure are described in the Rules of Procedure.

## Art. 7 End of membership

Any member may, at any time, resign from the Association. The resignation must be notified in writing to the board of directors and will be effective by fulfilment of all obligations to the Association.

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

a) failure to comply with financial or other commitments. Details on execution and procedure are described in the Rules of Procedure.

b) activities that are detrimental to the European Pulmonary Fibrosis Federation or violate the Association's articles of association or Rules of Procedure.

Any renewal of full membership (following an exclusion) will require the support of a majority of three quarters of present or represented members at a board of directors 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 meeting. The renewal will only enter into force after the aforementioned confirmation by the general meeting.

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 meeting;
- b. an executive organ, namely the board of directors
- c. a Secretariat may be appointed if the board of directors deems this necessary.

## Art. 9 General meeting

1. Powers -

The following exclusive powers can only be executed by the general meeting:

a. change the articles of association;

- b. appoint and dismiss the board members, the external auditor and determine their remuneration;
- c. approve accounts and budgets, propose and approve an annual provisional budget;
- d. define the mission of the board and grant discharge to the board members;
- e. decide on the voluntary dissolution of the Association;
- f. accept and exclude full members;

### 2. Composition

The general meeting consists of all members. Only full members have the right to vote. Every full member holds one vote. Associated members and others invited by the board of directors can attend the general meeting, however without the right to vote.

## 3. Meetings

The general meeting is convened annually by the President. The general meeting can meet in an Extraordinary general meeting, at the request of the majority of members of the board of directors or the general meeting.

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

4. Decision-making

The general meeting can only deliberate when one-half of the full members are present or represented, unless the articles of association explicitly state otherwise. The decisions mentioned under Article 9.1 of the articles of associations may only be taken when the meeting is composed of two thirds of the full members present or represented. 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 articles of association.

Exceptional decisions, for example inclusion of a new member, exclusion of a full member or amendment of the articles of association, 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 meeting will be recorded in a register, signed by a member of the board of directors 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 meeting will be sent to all members in the form of a report within four weeks.

#### Art. 10 Board of directors

1. Powers

The board of directors can undertake all activities of an executive nature that are needed or support the realisation of the objectives of the Association, excluding those activities that fall under the competences of the general meeting.

## 2. Election and composition

The members of the board of directors (the board) are elected by the general meeting by a simple majority for a term of two years. The mandate of a board member can always be renewed.

The board of directors is composed of at least three persons, and a maximum of nine persons. The board of directors elects amongst its members a President and a Secretary. The board of directors may appoint specialist roles carried out by people outside the board, such as treasurer or other specialists.

The position of President can only be taken up for two consecutive terms of two years each by the same person. The general meeting confirms by simple majority the appointment of the President and of the Secretary. If the appointment is not confirmed, the board of directors will submit a new proposal to the general meeting.

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 elected to the board of directors.

Should two full members be located in the same country and should there be more than one candidate to the board of directors 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 fulfilment of its objectives. The members responsible for the day-to-day management bear no personal liability for the commitments of the Association. They are only responsible for the execution of their assigned duties and for any shortcomings in the management of these duties (article 2:56 and 2:57 CCA). Members do not enter into any personal liability for commitments made by the Association.

The President is the head of the Association and presides over both the general meeting and the meetings of the board of directors.

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 board of directors 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 specialists roles, such as Treasurer, who may or may not be a member of the board, carries out the duties given by and in accordance with the instructions of the board.

## 4. Termination, dismissal, discontinuation

Membership of the board of directors is terminated by the discontinuation, resignation, or exclusion of the represented member, or 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 above-mentioned reasons, the board of directors can appoint a temporary substitute who finishes the mandate of their predecessor.

Members of the board of directors can be dismissed by the general meeting that will decide by a majority of three quarter of present or represented members.

Pursuant to article 2:7 of the Belgian law establishing the Code of Companies and Associations (CCA) of March 29 2019, all documents concerning the appointment, dismissal or discontinuation of members of the board, prepared in accordance with the law, will be, in view of their deposition in the legal file, notified to the registry of the business court and will, at the expense of the Association, and be published in the Annexes to the *Moniteur Belge/ Belgisch Staatsblad*.

## 5. Decision-making

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

The board of directors can only deliberate legitimately when at least the majority of its members is present.

Decisions of the board of directors 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 board of directors and kept at the address of the registered office of the Association.

## 6. External representational powers

The board of directors 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 board of directors, 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 board of directors.

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 meeting.

7. Advisors

The board of directors 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. From January 2023 the financial year will run from 1 January to 31 December each year.

The board of directors shall provide an annual written report to the general meeting. This report should be sent to all members at least six weeks before the general meeting 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 3:47 of the Belgian law establishing the Code of Companies and Associations (CCA) of March 29, 2019, be filed with the Belgian National Bank.

The general meeting shall appoint an external auditor or, if the law requires 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

Each meeting invitation (e.g. annual general meeting, 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.

## Art. 13 Modification of the articles of associations

The proposals for amending the articles of association may be submitted by the board of directors or by at least three full members of the general meeting, 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 articles of association may be amended at any general meeting, on the condition that two thirds of the full members is present or represented.

The board of directors will inform all members at least one month in advance of the date and venue of the general meeting, where the amendments will be discussed, and share the text of any amendments proposed.

A decision on amending the articles of association 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 meeting 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 articles of association will be effective only after approval, if need be, by the competent authority pursuant to article 2:5 §4 CCA, and after publication in the Annexes to the Moniteur Belge/ Belgisch Staatsblad in accordance with article 2:13 CCA.

## Art. 14 Dissolution of the Association

The board of directors determines the method of dissolution and liquidation of the Association that should be presented and approved by the general meeting through a three quarters majority. Any

remaining funds will be transferred to a European-wide non-profit organisation that supports research in 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 meeting.

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

The coordinated version of the Rules of Procedure is dated [DATE TO BE INCLUDED].

## Art. 16 Others

For anything that is not provided or laid down in these articles of association, the conditions laid out in the Belgian law establishing the Code of Companies and Associations (CCA) of March 29 2019 concerning international non-profit associations will apply.

These revised articles of association were adopted at the general meeting held in July 2022. In case of legal dispute, the Dutch version is deemed authentic.

Of this Act are 3 original copies were signed on [Date] by founders in opening paragraph.

Name and signature of all founders and proxy holders.