Statutes

of the

Alpha-1 Europe Alliance

Date: 17.10.2023

Alpha-1 Europe Alliance asbl
Maison des Associations Internationales
Rue Washington 40
1050 Brussels
Belgium

Registration Number
1001 288 636

FOREWORD / INTRODUCTION

Between the undersigned, being natural persons:

- **Alpha-1 Plus asbl**, having its seat at [redacted] represented by Mr. Frank Willersinn [redacted]
- **Alpha-1 Deutschland e.V.**, having its seat at [redacted] represented by Mr. Heinz Artur Dr. Stutzenberger, [redacted]
- **Alpha-1 UK Support Group** (charity), having its se[redacted] UNITED KINGDOM, hereby validly represented by Ms. Karen Tracey Kim O'Hara residing at [redacted]
- **Associazione Nazionale Alfa-1AT**, having its seat at [redacted] ITALY, hereby validly represented by Ms. Cristina Emanuela Barbiero [redacted]
- **Associacion Alfa-1 Espagna**, having its seat at [redacted] Compostela, SPAIN, hereby validly represented by Ms. Elena Goyanes Vilar residing a[redacted]
- **Alpha-1 Schweiz**, having its registered seat [redacted] validly represented by Ms. Renate Shashoua-Fasel r[redacted] SWITZERLAND.

herinafter the "**Founding Members**".

This incorporation document may be executed in any number of counterparts, each of which, when executed and delivered, shall be deemed to be an original, and all of which, taken together, shall constitute one and the same incorporation document. The date of incorporation of the association "Alpha 1-Europe Alliance ASBL" (hereinafter referred to as the "**Association**"), for all legal purposes, shall be the date on which the last Founding Member executes its counterpart of this incorporation document.

ARTICLES OF ASSOCIATION OF ALPHA-1 EUROPE ALLIANCE

SECTION I – NAME, LEGAL FORM, OFFICE, DURATION, PURPOSE AND OBJECT

ARTICLE 1 – Name and legal form

1.1 The name of the association is Alpha-1 Europe Alliance (the "Association").

1.2 The Association is a non-profit association governed by the Book 9 and any other provisions of the Belgian Code of Companies and Associations dated 23 March 2019 (the "Code") applicable to non-profit associations.

ARTICLE 2 - Office

2.1 The office of the Association is located in Brussels. It may be transferred to any other place in Belgium by decision of the Board of Directors, as long as the transfer does not imply a change of linguistic regime.

ARTICLE 3 - Duration

3.1 The Association is established for an unlimited period of time.

ARTICLE 4 – Purpose and Object (activities)

4.1 The non-profit purpose of the Association is to represent among international stakeholders its Members and more broadly all people living with Alpha-1 Antitrypsin Deficiency ("AATD") in Europe and advocate for access to timely diagnosis, best individualised care, and holistic therapies by raising awareness, promoting research, and empowering Alpha-1 national patient organisations.

4.2 The object (i.e. the activities) of the Association is to:

a) Represent the voice of the European Alpha-1 patient community among European and international stakeholders,
b) Advocate for pathways to access to timely diagnosis and the best existing and future treatment and holistic care,
c) Foster research on AATD aimed at finding a cure,
d) Serve as the European point of contact to support patients' and experts' early engagement in R&D and in the design and participation of clinical trials,
e) Raise awareness, educate, and train health care providers, specialists, policymakers, and the general public on AATD,
f) Support national Alpha-1 patient organisations in strengthening their capacities and reach;
g) Gather and analyse statistical data;
h) Organise congresses, seminars, workshops and other programs and meetings at international and national levels;
i) Issuing publications and be the owner of copyrights and any other intellectual property rights in all media.

4.3 In furtherance of its non-profit purpose, the Association will collaborate closely with sister organisation(s) at the international level or from other regions of the world. Similarly, the Association may collaborate with other relevant organisations on topics of common interest.

4.4 Furthermore, the Association may develop, support, incorporate, constitute, establish, participate in, and have interests (including holding shares, bonds, warrants, options, participations and/or investments, etc.) in any legal entities governed by Belgian or foreign law, commercial or non-commercial, non-profit or for-profit, private or public or semi-public, with or without legal personality, having a purpose and activities similar to those of the Association.

4.5 The operating area of the Association is EUROPE. For the purpose of these Articles of Association, the word "EUROPE" or "EUROPEAN" designates (the territory of) the countries being members of the Council of Europe. The Association can also establish relationships, contacts, and partnerships with stakeholders based in other geographic areas where this is strategically appropriate for realising the non-profit purposes set out above.

4.6 The Association may engage in any activities to fulfil its purpose and further its objectives.

4.7 The Association may carry out commercial activities without quantitative limits provided that the profits generated by these activities are entirely and at all times entirely allocated to the realisation of the non-profit purpose of the Association.

SECTION II - MEMBERSHIP

ARTICLE 5 - Membership

5.1 The Association shall have two (2) categories of membership:

a) Full Membership ("**Full Members**"); and
b) Associate Membership ("**Associate Members**");

collectively, the "**Members**".

5.2 The Founding Members (as defined in Article 6) shall be the first Full Members.

5.3 The obligations of the Members shall be defined in the present Articles of Association.

5.4 Membership is *intuitu personae*/*intuitu firmae* (i.e. Membership has been granted to a natural/legal person because of its personal characteristics) and cannot be transferred or assigned.

5.5 The Members shall be bound by the provisions of the present Articles of Association, the Internal Rules and by other rules or regulations duly adopted by the General Assembly in relation to the activities of the Association.

5.6 The Association respects the individuality of its member organisations. It recognises and appreciates the diversity of viewpoints among its members and strives to achieve consensus on issues of common interest linked to the Association's Membership.

ARTICLE 6 – Founding Members

6.1 The following legal entities are the Founding Members of the Association at its incorporation:

a) Alpha-1 Plus, a non-profit association under Belgian law (ASBL), registered with the Crossroads Bank for Enterprises under the enterprise number 0541.655.324;
b) Alpha-1 Deutschland e.V., an *Gemeinnütziger Verein (*i.e. non-profit association) under German law;
c) Alfa1-AT Italia Onlus, a non-profit association under Italian law;
d) Alfa-1 Espagna, a non-profit association under Spanish law;
e) Alpha-1 Schweiz, a V*erein* (i.e. association) under Swiss law; and
f) Alpha-1 UK, a non-profit association under UK law.

ARTICLE 7 - Full Membership

7.1 The number of Full Members of the Association shall not be less than two (2) Full Members.

7.2 Full Membership is open and accessible to all legal entities meeting the following criteria:

a) Being validly incorporated and registered or accepted as *bona-fide* organisations within their own country;

b) Being a regional, national, or multinational registered patient organisations in Europe providing support for people diagnosed with AATD or associated diseases, and their friends, family members, and caregivers.
c) Committing to the Association's value;
d) Complying with the following criteria:

i. Legitimacy

To be admissible as a Full Member, an applicant organisation should have its registered office in Europe. If the applicant organisation does not have its registered office in Europe, additional information needs to be provided demonstrating European focus and activities.

ii. Democracy

To be admissible as a Full Member, an applicant organisation should have governing bodies, which are elected democratically by their members, who may be patients, caregivers, or the organisation's elected representatives.

iii. Accountability and Consultation

To be admissible as a Full Member, public statements and opinions of the applicant organisations should reflect the views and opinions of their members and appropriate consultation procedures with those members should be in place and used in practice.

iv. Transparency

The applicant organisations should disclose their sources of funding and provide their audited financial accounts, or if not available, accounts legally filed in accordance with the provisions of national law and any other documents considered useful by the Board of Directors in relation to all the criteria required by this Article 7.

Only organisations, which fulfil the above criteria, may become Full Members of the Association.

7.3 There is no limit to the number of Full Members per country.

ARTICLE 8 – Associate Members

8.1 The following natural/legal persons can apply for Associate Membership:

a) Legal entities being regional, national, or international registered patient organisations in Europe which provide support to people living with AATD which:
   i. do not comply with the Full Membership criteria;
   ii. uphold the views, objectives and values of the Association; and
   iii. adhere to the principles set out in Article 7.2., d) (i.e. legitimacy, democracy, accountability and consultation and transparency).

b) Natural persons, such as active individuals, members of their families, and other persons who wish to support AATD advocacy efforts in Europe, are able to become Associate Members insofar as they are domiciled in countries where no national organisation representing (potential) AATD patients is established. If, however, such national organisation is to be founded in the country of the domicile of a natural person Associate Member, such individual will automatically lose his or her Associate Membership and is requested to remain involved with Alpha-1 Europe Alliance, but through the national organisation from his or her domicile.

8.2 Associate Members will be entitled to attend the meetings of the General Assembly without voting rights and to participate in, and receive information about, the activities of the Association.

8.3 If an Associate Member meets the Full Membership criteria following its admission, its membership status can be upgraded to Full Membership, subject to the General Assembly's approval. An Associate Member must be nominated and seconded by two (2) other Full Members for the upgrade to Full Membership.

ARTICLE 9 – Admission of Members

9.1 Any candidate to Membership shall send its application to Membership to the Board of Directors and shall provide the following information and documents together with its application:

- an application stating that they wish to join the Association and that they accept to be bound by the provisions of the Articles of Association, the Internal Rules and the Code of Conduct;
- their incorporation documents and their articles of association;
- documents on incorporation and registration as *bona-fide* organisations within their own country (see also Article 7.2, (a));
- their permanent address including their contact details and any other relevant details (e.g. foreign languages spoken);
- the estimated number of individual members or member organisations representing AATD registered in their organisation; and where they represent more disease areas, the number of members of their AATD section;
- a copy of their latest audited accounts, or if not available, accounts legally filed in accordance with the provision of national law.

9.2 After verifying that the conditions to Membership are complied with, the Board of Directors will issue a non-binding opinion on the (non-)admission of the Member to the General Assembly within forty-five (45) calendar days following the receipt of the candidacy.

9.3 Considering the non-binding opinion of the Board of Directors, but in line with the legal powers attributed to the General Assembly in article 9:12, 2° of the Code and considering the Membership criteria as set out in article 7.1 and 8.2 of these articles of association, the General Assembly shall resolve on the admission of the candidate to Membership. The resolutions of the General Assembly regarding the (non-)admission of a Member are final (non-appealable), sovereign and the General Assembly shall not give reasons for its decisions. However, without prejudice to the preceding sentence, the General Assembly shall give a formal motivation for its decision when it resolves to depart from the opinion of the Board of Directors.

9.4 The General Assembly can resolve on the admission of a candidate to Membership without having to wait for the non-binding opinion of the Board of Directors if it has not been issued in the aforementioned period of forty-five (45) calendar days.

ARTICLE 10 – Annual Membership Fees

10.1 The Members shall be required to pay annual membership fees as determined by the General Assembly. The membership fees might vary for Full Members and Associate Members. In addition, the membership fees might vary in the Associate Members category depending on whether the member is a legal entity or a natural person. Annual membership fees shall not exceed EUR 5,000.

10.2 Without prejudice to Article 12, if a Member is in default of payment of its annual membership fees thirty (30) calendar days after a reminder has been sent to it by the Treasurer, its membership rights (including its voting rights if it is a Full Member) shall be automatically and immediately suspended until the payment in full of the outstanding membership fees.

10.3 The Members which join the Association during a financial year shall pay an amount of the annual membership fees for its membership category *pro rata*.

10.4 Each year, the Board of Directors shall resolve on the invoicing procedure and the deadline for the payment of the annual membership fees.

ARTICLE 11 – Resignation

11.1 Members are free to resign from membership of the Association at any time by notifying their resignation by email with acknowledgment of receipt or by registered post to the President.

11.2 The resignation will take effect at the end of the financial year during which the resignation has been notified. The full Annual Membership Fee and other financial contributions due for that financial year remain due by the Member concerned.

11.3 A Member is deemed to have resigned if the Member is in one of the following situations:

a) Voluntary/as of right/judicial dissolution/winding-up;
b) Bankruptcy or other insolvency procedures of a similar nature under the laws of any jurisdiction;
c) Administration or judicial reorganisation;
d) Undergoes any sort of transaction (such as a merger, a transfer of a branch of activities, a change of control, transfer of assets, etc.) having a considerable impact on the Member's assets or the ownership structure of the Member.

11.4 Resigning Members or their legal successors shall have no claims against the assets of the Association.

Article 12 – Exclusion

12.1 A Member which (i) ceases to fulfil the definition of the Membership category to which it belongs as set out in Articles 7 and 8 of these Articles of Association, (ii) does not comply entirely with these Articles of Association, the internal rules, the Code of Conduct (as the case maybe) and any resolutions validly adopted by the bodies of the Association, (iii) does not pay its membership fees within the prescribed period, (iv) harms the interest of the Association, (v) acts in a manner contrary to the values and ethics of the Association, (vi) has substantially amended its activities, or (vii) for any other proper reasons may be excluded from membership by the General Assembly upon proposal of the Board of Directors.

12.2 Before proposing the exclusion of a Member to the General Assembly, the Board of Directors shall provide in writing thirty (30) calendar days the relevant facts and the reasons for the proposed exclusion. The concerned Member will be authorised to provide its remarks in writing up to fifteen (15) calendar days before the meeting of the Board of Directors. Taking into account all factual and legal circumstances (including the written remarks of the concerned Member as the case may be), the Board

of Directors shall resolve (not) to propose the exclusion of the concerned Member to the General Assembly.

12.3 Upon proposal of the Board of Directors, the General Assembly can resolve to exclude a Member provided that the concerned Member has been convened at the meeting of the General Assembly and has been granted the possibility to defend itself during the meeting of the General Assembly and prior to vote regarding its exclusion. The General Assembly shall be validly constituted to resolve on the exclusion of the concerned Member if at least two-thirds (2/3) of the Full Members are present or represented and the decision regarding the (non-)exclusion shall be validly adopted if it obtains at least two-thirds (2/3) of votes cast by the Full Members present or represented. The resolutions of the General Assembly regarding the exclusion of a Member shall be final (non-appealable), sovereign and the General Assembly shall give reasons for its decisions.

12.4 The decision to exclude a Member shall be notified to the concerned Member by the President by email with acknowledgment of receipt or by registered letter within fifteen (15) calendar days following the decision of the General Assembly.

12.5 The membership rights of the concerned Member shall be suspended during the whole procedure of exclusion until the decision of the General Assembly.

12.6 Excluded Members or their legal successors shall have no claims against the assets of the Association and no claim regarding the fees paid to the Association.

ARTICLE 13 – Register of Members

13.1 The Secretary shall keep a register of Members, in electronic format, at the registered office of the Association. This register shall contain the following data: (i) for Members being natural persons, (a) their first name and last name, (b) their date of birth, (c) the address of their domicile, and (iv) their contact details (i.e. phone number and e-mail address), and (ii) for Members being legal entities, (a) the legal name, (b) the legal form, (c), the address of the registered office, (d) the enterprise number/VAT number or any other equivalent identification number, and (e) the contact details of the main representative of the Member organisation.

13.2 In addition, the decisions regarding the admission, the resignation and the exclusion of Members shall be registered in the register of Members by the Secretary, as soon as the Board of Directors or the General Assembly has adopted such a decision.

SECTION IV - GENERAL ASSEMBLY

ARTICLE 14 – Composition and voting rights

14.1 The General Assembly is composed of all the Full Members and the Associate Members.

14.2 Each Member being a legal person shall be represented by an individual appointed by the Member organisation (hereafter: the "**Representative**"). If a Member's activities have a broader scope than AATD, the Representative will be a member of their AATD section.

14.3 Each Full Member shall have one (1) vote at the General Assembly.

14.4 Associate Members can attend meetings of the General Assembly but shall not have voting rights at the General Assembly.

14.5 The General Assembly shall be chaired by the President or, if the President is unable to attend, by the Vice-President. If either of these parties is absent or unwilling to chair the General Assembly, the role of chairperson will pass to a director that will be designated by the members on a consensus basis (the "Chairperson"). The Chairperson will consist, together with persons appointed at the beginning of every meeting (if any), the bureau of that General Assembly.

14.6 Directors can attend meetings of the General Assembly without voting rights but with the right to be heard. Without prejudice to the preceding sentence, each director which has been designated as a Representative of its Member shall be authorised in this specific capacity for the Full Member he/she represents.

14.7 The President/the Board of Directors can invite some third parties (including candidates to Membership) to attend, without voting rights, to a (part of the) meeting of the General Assembly. Upon authorisation from the President/Board of Directors, these third parties will be granted with the right to be heard.

ARTICLE 15 – Powers of the General Assembly

15.1 The General Assembly shall have the powers specifically granted upon it by law (in particular by article 9:12 of the Code) or the Articles of Association. The General Assembly has *inter alia* the following powers:

a) Upon proposal of the Board of Directors, the establishment of a strategic plan, annual budget and working plan;
b) Upon proposal of the Board of Directors, the approval of the annual accounts and the budget of the Association;
c) The appointment and dismissal of the directors, the decision to grant them or not a remuneration and the level of their remuneration if any;
d) The appointment and the dismissal of a statutory auditor, if required by law, and the determination of their remuneration;
e) The discharge to be granted to the directors and the statutory auditor and as the case maybe the decision to take legal actions against the directors and the statutory auditor;
f) The amendments to the Articles of Association;
g) The dissolution of the Association and the distribution of any net assets;
h) The admission of Associate and Full Members;
i) Upon proposal of the Board of Directors, the exclusion of Members;
j) The setting of annual membership subscription rates for both Full Members and Associate Members;
k) The appointment and dismissal of an accountant and the determination of its remuneration;
l) The appointment and dismissal of internal auditor(s), and the determination of its (their) remuneration;
m) The hiring and the dismissal of consultants and employees with the exclusion of the staff assisting the Chief Executive Officer in his/her functions;
n) The conversion of the Association into an international non-profit association (in French: "*association internationale sans but lucratif*", abbreviated: "*AISBL*"/ in Dutch: "*internationale vereziging zonder winstoogmerk*", abbreviated "*IVZW*"), into a cooperative company approved as a social enterprise and into an approved cooperative social enterprise; and
o) To make or accept the contribution of a universality free of charge.

ARTICLE 16 – Meetings of the General Assembly

16.1 An ordinary meeting of the General Assembly shall be held annually at the latest six (6) months after the date of closing of the preceding financial year to approve the annual accounts and the budget of the Association (hereafter: "**Annual General Assembly**").

16.2 Extraordinary meetings of the General Assembly may be convened on the initiative of the Board of Directors, or by a request of at least twenty percent (20%) of the Full Members to resolve on (i) the amendment of these Articles of Association, or (ii) the dissolution and liquidation of the Association (hereafter: "**Extraordinary General Assemblies**").

16.3 A special meeting of the General Assembly (i.e. a meeting which is a neither an Annual General Assembly nor an Extraordinary General Assembly) shall be convened at any moment on the initiative of the Board of Directors, or by a request of at least twenty percent (20%) of the Full Members. In the latter case, the Board of Directors convenes the General Assembly within twenty-one (21) calendar days of the request to convene, and the General Assembly is held no later than the fortieth (40th) day following this request, unless otherwise provided by the Articles of Association.

ARTICLE 17 – Convening formalities. Agenda.

17.1 Notice of the meeting shall be given to the Members by the President at least fifteen (15) calendar days before the date of the meeting. The notice of the meeting shall indicate the date, the hour and place of the meeting as well as its agenda. Furthermore, the convening notice shall indicate whether or not the Members can participate to the meeting via electronic means of communication and/or vote electronically. The agenda and the supporting documentation shall be attached to the convening notice.

17.2 One twentieth ($1/20^{th}$) of the Full Members acting together shall be entitled to submit proposals of additional items to be registered in the agenda of the next meeting of the General Assembly to the Board of Directors/President up to five (5) calendar days before the meeting. In such a case, the President/the Board of Directors shall inform the Members and the directors of the additional items on the agenda at the latest three (3) calendar days before the meeting of the General Assembly.

ARTICLE 18 – Proxies

18.1 A Full Member may be represented by another Full Member pursuant to a written proxy delivered to the Secretary of the Association one (1) calendar day prior to the opening of the meeting. No Full Member shall hold more than one (1) proxy.

ARTICLE 19 – Presence quorums and voting majority

19.1 Unless otherwise provided for in the Code, the General Assembly shall be validly constituted and authorised to take resolutions regardless of the amount of Full Members present or represented at the meeting.

19. 2 Unless otherwise provided for in the present Articles of Association or by the Code, decisions of the General Assembly shall require a simple majority of the Full Members present or represented by

proxy. In case of a tie vote, the Full Member whose Representative is the President shall have the casting vote and in its absence, the Full Member whose Representative is the Vice-President. Abstentions, invalid votes and blank votes shall not be taken into account.

ARTICLE 20 – Meetings via electronic means of communication and unanimous written resolutions

20.1 Meetings of the General Assembly can be organised in person or by tele/videoconference provided that it is authorised by the Board of Directors in the convening notices. In such a case, the meeting shall be validly held even if all or some of the Members are not physically present or represented, but participate in the deliberations by any electronic means of communication enabling the Members to hear and speak to each other directly, such as a telephone, video or web conference and allowing to check the identity of the Members. In such a case, the Members shall be deemed to be present. The bureau must be physically present at the location where the General Assembly is held and will sign the meeting minutes after the General Assembly was held via electronic means of communication.

20.2 Full Members may also unanimously adopt in writing all decisions which fall within the powers of the General Assembly, with the exception of (i) the amendment of these Articles of Association and (ii) the exclusion of Members.

ARTICLE 21 – Register of the minutes

21.1 All Members will be informed about the decisions taken at the General Assembly. The resolutions of the General Assembly shall be recorded in minutes signed by the Chairperson, and those Full Members which so wish, and shall be kept in a register of the minutes of the General Assembly. The register shall be held at the registered office of the Association and can be consulted by the Members.

SECTION V - THE BOARD OF DIRECTORS

ARTICLE 22 - Composition of the Board of Directors, number of directors and duration of the mandate

22.1 The Association shall be administered by the Board of Directors, consisting of minimum four (4) directors and maximum seven (7) directors (i.e. members of the Board of Directors).

22.2 The Board of Directors shall be composed as follows:

a) The President;
b) The Vice-President(s);
c) The Secretary;
d) The Treasurer;
e) One (1) up to three (3) directors elected by the General Assembly.

The President, the Vice-President(s), the Secretary and the Treasurer shall be hereinafter referred to as the "**Officers**".

22.3 All directors shall serve for a period of three (3) years but shall be eligible for re-election without limit.

22.4 The term of office of the directors shall not be remunerated. Without prejudice to the preceding sentence, the Association shall reimburse any reasonable expenses incurred by the directors in attending meetings of the Board of Directors or to attend event organised in the framework of the activities of the Association, upon the presentation of the relevant invoice.

ARTICLE 23 - Election and end of the mandate of the directors and the officers

23.1 The directors shall be elected by the General Assembly from the candidates nominated by the Full Members. Persons wishing to become directors of the Association shall send their application to the Secretary and shall be endorsed by at least one (1) Full Member of the Association.

23.2 The President, one or more Vice-President(s), a Secretary, a Treasurer shall be elected by the General Assembly from the Representatives of the Members.

23.3 A director's mandate expires on the expiry of the term of office. The term of office of a director shall terminate as of right and with immediate effect (i) in the event of death or incapacity, or (ii) if, as the case may be, a director ceases to be employed by or is otherwise no longer connected with the Member which he/she represents or (iii) if the Member which the director represents, as the case may be, ceases, for any reason whatsoever, to be a Member of the Association, or (iv) if the Member which the director represents, if any, is under provisional administration, bankruptcy, judicial reorganisation, dissolution or liquidation, or is subject to insolvency proceedings of a similar nature under the laws of any jurisdiction, or (v) if the Member which the director represents, if any, has substantially changed its activities and does not meet anymore the criteria to Full Membership.

23.4 Directors may be dismissed by the General Assembly at any time, for any reason that may be considered contrary to the purposes, the values or the operation of the Association, by a vote of at least two-thirds (2/3) of the Members present or represented. The director concerned shall have the right to be heard before a final decision is made unless the Ethics Committee decides that such hearing by the General Assembly would expose other individuals to unfair treatment, or breach of confidentiality in a significant way.

23.5 Directors may also resign at any time by notifying their resignation by email with acknowledgment of receipt or by registered letter to the Secretary of the Association.

23.6 With the exception of the directors referred to in Article 22.2, a) through d), in case the mandate of a director expires before its term, the Board of Directors will appoint via co-optation a new director which for the remaining duration of the term of the director being replaced. The first upcoming meeting of the General Assembly must confirm the appointment of the director that has been co-opted by the Board of Directors. In the event of confirmation, the co-opted director completes his predecessor's term of office. In the event there is no confirmation, the co-opted director's term of office expires at the end of the meeting of the General Assembly, without prejudice to the regularity of the composition of the Board of Directors up to that date.

23.7 If the mandate of a director comes to an end for any reason whatsoever, the director shall not be entitled to any claim for compensation against the Association or its assets.

ARTICLE 24 – Powers of the Board of the Directors

24.1 The Board of Directors shall have all the powers necessary to pursue the non-profit purpose of the Association, with the exception of those powers which are specifically granted to other bodies of the Association by law or these Articles of Association. The Board of Directors shall act as a collegial body.

24.2 The Board of Directors shall have the following powers in particular:

a) The transfer of the registered office of the Association where this does not imply a change in the language of these Articles of Association in accordance with the legal provisions on the use of official languages in Belgium;
b) The determination of the strategies and policies of the Association;
c) The general management and administration of the Association;
d) Controlling budget expenditure and allocating the budget;
e) Convening meetings of the General Assembly;
f) Implementing the decisions of the General Assembly;
g) Issuing a non-binding opinion to the General Assembly regarding the admission of new Members;
h) Proposing to the General Assembly to exclude a Member;
i) Preparing the draft annual accounts and the draft budget to be submitted to the General Assembly for approval;
j) Adopting proposals to be submitted to the General Assembly; and
k) Appointment of a director via co-optation.

24.3 Each year, prior to the approval of the annual accounts by the Annual General Meeting, the Board of Directors shall report to the Annual General Assembly on the annual activity of the Association, which shall include at least information concerning (i) the use of the budget, (ii) the determination of the method of calculation and the amount of the annual Membership fees, and (iii) the activities of the Association.

24.4 The Board of Directors may at any time delegate specific powers to one or more directors or to other persons, with or without the power to sub-delegate within the legally authorised limits.

ARTICLE 25 – Powers of the Officers (President, Vice-President(s), Treasurer and Secretary)

25.1 The President will be Chairperson of the Board of Directors and shall also be the Chairperson of the General Assembly, in accordance with Section IV of the present Articles of Association. In addition, the President shall have the following powers:

a) Convene meetings of the General Assembly Board of Directors;
b) In collaboration with the Secretary, prepare the agenda for meetings of the General Assembly and the Board of Directors;
c) Adopt the agenda for meetings of the General Assembly and the Board of Directors;
d) Sign and approve the minutes of the meetings of the General Assembly and of the Board of Directors;
e) Issue the casting vote in case of a tie vote during meetings of the Board of Directors; and
f) Act as conciliator when differences of opinion arise, both within the Association and vis-à-vis third parties.

25.2 In the event the President is unavailable, the Vice-President will exercise the powers of the President.

25.3 The Secretary shall be responsible for the drafting of the minutes, the keeping of the different registers of the Association, the notification of the meetings that are called and the preparation of the agenda of such meetings in consultation with the President.

25.4 The Treasurer shall be responsible for the proper management of the central funds, for receiving contributions on behalf of the Association, for publishing the accounts of the Association and for recommending auditors to the General Assembly.

ARTICLE 26 – Convening formalities. Agenda.

26.1 The Board of Directors shall meet at least once per year. It shall also meet upon specific notice of its President or upon request of at least half (50%) of the directors.

26.2 Convening notices for meetings of the Board of Directors shall be given by the President to the directors by ordinary post or by any other written means of communication (including e-mail) at least five (5) calendar days before the meeting. The convening notices shall state the date, time and place of the meeting. In addition, the notice shall state whether directors may participate in the meeting by electronic means of communication and/or may vote electronically. The agenda and the relevant documents required for discussion will be attached to the notices of meeting. The agenda for meetings of the Board of Directors will be drawn up and adopted by the President.

26.3 Without prejudice to Article 26.2, each director acting alone shall be entitled to submit proposals of additional items to be registered in the agenda of the next meeting of the Board of Directors to the President up to three (3) calendar days before the meeting. In such a case, the President shall inform the directors of the additional items on the agenda at the latest one (1) calendar days before the meeting of the Board of Directors.

ARTICLE 27 – Proxies

27.1 A director may be represented by another director pursuant to a written proxy delivered to the Secretary of the Association one (1) calendar day prior to the opening of the meeting. No director shall hold more than one (1) proxy.

ARTICLE 28 – Presence quorum and voting majorities

28.1 The Board of Directors may validly deliberate and take decisions if at least half (50%) of the directors are present or represented. Resolutions of the Board of Directors shall require the simple majority of the directors present or represented. Each director shall have one (1) vote.

28.2 In the event of a tied vote, the President shall have a casting vote and in his absence the Vice-President who has been appointed to chair the meeting. Abstentions, invalid votes and blank votes shall not be taken into account.

ARTICLE 29 – Meetings via electronic means of communication and unanimous written resolutions

29.1 A duly convened meeting of the Board of Directors shall be validly held even if all or some of the directors are not physically present or represented, but participate in the deliberations by any means of telecommunication enabling the directors to hear and speak to each other directly, such as a telephone, video or web conference. In such a case, the directors shall be deemed to be present.

29.2 Provided that the possibility of voting electronically during the meeting of the Board of Directors has been mentioned in the notice convening the meeting, the directors may vote electronically during the meeting. The Chairman shall ensure that the electronic voting system makes it possible to verify the status and identity of the directors and to check that the votes have been cast within the prescribed. A duly convened meeting of the Board of Directors shall be validly held even if all or some of the directors are not physically present or represented, but participate in the deliberations by any means of telecommunication enabling the directors to hear and speak to each other directly, such as a telephone, video or web conference. In such a case, the directors shall be deemed to be present.

29.3 The directors may take unanimous written decisions on all matters falling within the scope of the powers of the Board of Directors.

ARTICLE 30 – Conflict of interests of a patrimonial nature

30.1 If a director has a direct or indirect pecuniary interest which is opposed to the interests of the Association, the director concerned must inform the other directors before the Board of Directors takes a decision. His/her declaration and explanation of the nature of the conflicting interest must be included in the minutes of the meeting of the Board of Directors which is to take the decision. The Board of Directors may not delegate this decision.

30.2 If, on the balance sheet date for the last financial year for which the accounts have been closed, the Association exceeds more than one of the criteria referred to in article 3:47, § 2 of the Code, the Board of Directors shall describe in the minutes the nature of the aforementioned decision or operation and its financial consequences for the Association and shall justify the decision that has been taken. This part of the minutes is included in full in the management report or in the document filed at the same time as the annual accounts.

30.3 A director with a conflict of interests may not take part in the deliberations of the Board of Directors concerning such decisions or transactions, or in the vote relating thereto. If the majority of the directors present or represented have a conflict of interest, the decision or transaction is submitted to the General Assembly; if the General Assembly approves the decision or transaction, the Board of Directors may implement it.

30.4 The aforementioned rules on conflicts of interests do not apply when the decisions of the Board of Directors concern customary transactions entered into under normal market conditions and guarantees for transactions of the same nature.

ARTICLE 31 – Register of the minutes

31.1 The resolutions shall be recorded in minutes and shall be signed by the Chairperson of the meeting and those members of the Board of Directors who so wish and shall be kept in a register of the minutes.

The register shall be held at the registered office of the Association and can be consulted by the directors.

SECTION VI - SUPPORT TO THE BOARD

ARTICLE 32 – Advisory Board, Working Groups and Advisory Groups

32.1 The Board of Directors may on an annual basis, designate advisors for specific projects. These advisors will have the right to attend meetings of the Board of Directors, without voting rights and with the right to be heard. Without prejudice to the above, the President can decide that the advisors cannot assist to some meeting(s) or part(s) of meeting(s) of the Board of Directors.

32.2 The Board of Directors may create a Medical Advisory Board which is a board of leading internationally recognised European Doctors specialised in AATD or related matters, to advise the Association on medical questions and to help promote the voice of patients in scientific events. The membership of the Medical Advisory Board will be reviewed on a 3 to 5 years basis to ensure best talents are included, but prolonged membership will be encouraged.

32.3 The Board of Directors may also create working groups or advisory groups to assist in the work of the Association. Any such group will have clearly stated objectives, membership, and time frame for its work. The Board of Directors may ask it to submit regular reports should it deem it necessary.

ARTICLE 33 – Daily management

33.1 *Election and end of the mandate of the* Chief Executive Officer

The Board of Directors may also appoint a Chief Executive Officer to support the ongoing operations of the Association.

The mandate of the Chief Executive Officer expires on the expiry of its term of office as decided by the Board of Directors. The term of office of a Chief Executive Officer shall terminate as of right and with immediate effect (i) in the event of death or incapacity, or (ii) if the Chief Executive Officer is under provisional administration, bankruptcy, judicial reorganisation, or is subject to insolvency proceedings of a similar nature under the laws of any jurisdiction.

The Chief Executive Officer can resign at any time from his/her mandate by sending a resignation letter to the Board of Directors. In such a case, the Chief Executive Officer shall continue to exercise its mandate until he/she is replaced by the Board of the Directors within ninety (90) calendar days, without prejudice to the provisions contained in a services agreement.

The Chief Executive Officer may be revoked at any time by the Board of Directors by simple majority of the votes of the directors present or represented.

33.2 *Powers of the* Chief Executive Officer

This person will be entrusted with all powers falling within the scope of the daily management of the Association.

In accordance with article 9:10, paragraph 2 of the Code, daily management includes both acts and decisions which do not exceed the needs of the day-to-day life of the Association and acts and decisions which, either because of the minor interest they represent or because of their urgent nature, do not justify the intervention of the Board of Directors.

The Chief Executive Officer shall also have the following powers:

f) he/she will support the President, Vice-President, Secretary and Treasurer, in their responsibilities;
g) he/she will make any proposals to the Board of Directors with regards to the operation of the Association, its strategies, projects, budgets, meetings or others and may represent, negotiate, organise and sign on behalf of the Association any agreements, reports, applications, representations or others deemed necessary for the proper operation of the Association, in line with decisions made by the Board of Directors; and
h) he/she will hire the staff of the secretariat/office of the Chief Executive Officer.

The Chief Executive Officer will report to the Board of Directors, and attend Board meetings (with exceptions of sessions that would result in a conflict of interest), but will not have any voting rights.

If no Chief Executive Officer is appointed in accordance with Article 33.1, the powers listed in the present Article 33.2 shall be exercised by the Board of Directors.

SECTION VII – CODE OF CONDUCT AND INTERNAL RULES

ARTICLE 34 – Code of Conduct and Internal Rules

34.1 The Board of Directors is competent to adopt, amend and revoke the Internal Rules, the Code of Conduct and any other internal regulations if any.

34.2 The meeting of the Board of Directors will be validly composed to resolve on the amendment of the Internal Rules and the Code of Conduct if at least half of the directors are present or represented and the decision to amend obtains at least a qualified majority vote of two-thirds (2/3) of the votes cast by the directors present or represented.

SECTION VIII - BUDGET AND ANNUAL ACCOUNTS

ARTICLE 35 – Budget and annual accounts

35.1 The financial year of the Association shall start on 1st January and shall end on 31 December (the "**Financial Year**").

35.2 Each year, the Board of Directors shall prepare the annual account and shall submit the same to the General Assembly for approval. The annual accounts, together with the yearly reports on the past fiscal year, shall be submitted with the budget and work plan for the current Financial Year.

35.3 The annual accounts and supporting documentation will be open for inspection by the Members.

35.4 The Treasurer will present an updated financial statement to the Board of Directors at each meeting.

ARTICLE 36 – Audit of the Annual Accounts

36.1 If required by law, the General Meeting shall appoint a statutory auditor from among the members of the "*Institut des Réviseurs d'Entreprise / Instituut der Bedrijfsrevisoren*" for a term of office of three (3) years.

36.2 If the Association is not legally obliged to appoint a statutory auditor, the General Assembly may nevertheless appoint an auditor to audit the annual accounts.

36.3 The statutory auditor, if any, shall prepare an annual report on the annual accounts of the Association. This report shall be submitted to the Ordinary General Meeting prior to the approval of the annual accounts.

SECTION IX – EXTERNAL REPRESENTATION OF THE ASSOCIATION

ARTICLE 37 – External representation of the Association

37.1 The Association is validly represented towards third-parties and before the courts as plaintiff or defendant in legal proceedings by the Board of Directors itself physically represented by its President, acting alone, or by two directors acting jointly, or by a proxy-holder (being a director or not) specifically appointed by the Board of Directors.

37.2 In the context of the daily management, the Association shall also be validly represented vis-à-vis third parties and in respect of all judicial acts (both before the judicial authorities and before the administrative courts) and extra-judicial acts by the Chief Executive Officer acting alone.

37.3 In addition, the Association shall also be validly represented vis-à-vis third parties, within the limits of their mandate(s), by one or more proxy-holder(s) validly mandated by the Board of Directors, by the President acting alone, or by two (2) directors acting jointly, or, in the context of the daily management, by the person delegated for day-to-day management acting alone.

SECTION X - AMENDMENT OF THE ARTICLES OF ASSOCIATION AND DISSOLUTION AND LIQUIDATION

ARTICLE 38 – Amendment of the Articles of Association

38.1 The Extraordinary General Assembly may only resolve on the amendment to the Articles of Association if (i) two-thirds (2/3) of the Full Members of the Association are present or represented and (ii) the resolution to amend the Articles of Association obtains two-thirds (2/3) of the vote cast by the Full Members present or represented. Without prejudice to the above, any amendment to the purpose and object for which the Association has been incorporated can only be adopted if such a decision obtains at least four fifth (4/5) of the votes cast by the Full Members present or represented. Abstentions, invalid votes and blank votes shall not be taken into account.

38.2 If the above-mentioned two-thirds (2/3) attendance quorum is not reached, a new Extraordinary General Assembly shall be convened in accordance with the conditions outlined in Article 17. This meeting will have the power to decide definitely and validly on the points of the agenda,

irrespective of the number of Members present or represented. However, the meeting shall be always composed of two (2) natural person being present.

38.3 The main terms of any proposal of amendment to the Articles of Association will be explicitly indicated in the convening notice or in a separate document that will be annexed to the convening notice that will be sent to the Members and the Directors.

38.4 The date on which the amendments to the Articles of Association will enter into force will be determined by the Internal Rules, if any, or by the decision of the General Assembly regarding said amendments to the Articles of Association.

Article 39 – Dissolution and liquidation of the Association

39.1 The Extraordinary General Assembly may only resolve on the dissolution and liquidation of the Association if (i) two-thirds (2/3) of the Full Members of the Association are present or represented and (ii) the resolution to amend the Articles of Association obtains four fifth (4/5) of the votes cast by the Full Members present or represented. Abstentions, invalid votes and blank votes shall not be taken into account.

39.2 If the above-mentioned two-thirds (2/3) attendance quorum is not reached, a new Extraordinary General Assembly shall be convened in accordance with the conditions outlined in Article 17. This meeting will have the power to decide definitely and validly on the points of the agenda, irrespective of the number of Members present or represented. However, the meeting shall be always composed of two (2) natural person being present.

39.3 At the occasion of the dissolution and liquidation of the Association, the Extraordinary General Assembly shall resolve on the following items: the appointment of one or more liquidators, the decision-making process of the liquidators if more than one liquidator is appointed, and the scope of their powers. In the absence of the appointment of one or more liquidators, all the directors shall be deemed to be jointly liable for the liquidation of the Association.

39.4 The General Assembly shall also decide on the allocation of the Association's net assets. Any net assets remaining after the liquidation shall be assigned to a private non-profit legal entity with a similar purpose to that of the liquidated Association or failing which, shall be used for a non-profit purpose. If no agreement can be reached by the Extraordinary General Assembly on the use of such liquidation proceeds, the residual amount will be transferred to the Belgian private foundation Lungs Europe (previously: European Lung Foundation). Should the Belgian private foundation Lungs Europe not exist anymore at that time, the net assets will be allocated to the French association EUROPEAN ORGANISATION FOR RARE DISEASES (EURORDIS).

SECTION XI - GENERAL PROVISIONS

ARTICLE 40 – General provisions

40.1 All matters not provided for in the present Articles of Association or the Internal Rules shall be governed in accordance with the provisions of the Code applicable to non-profit associations. In the event of a conflict between these Articles of Association and, where applicable, the internal rules, internal procedures or any other type of rules of the Association, these Articles of Association shall prevail.

40.2 The official language of the Association and of these Articles of Association is French. The work language of the Association is English.

40.3 The English version of the Articles of Association is a convenience translation for internal purposes. In case of disagreement between the two versions, the French version of the Articles of Association ("Statuts") shall always prevail and be binding.

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NON-STATUTORY TRANSITIONAL PROVISIONS

Upon the formation of the Association the Founding Members agree to the following non-statutory transitional provisions:

Closing of first financial year
The first financial year runs from the day of incorporation to 31 December 2024.

Date of first annual meeting
The first annual meeting will be held no later than 30 June 2025.

Appointment of directors
The founding members meet at a first special general meeting and unanimously resolve to appoint the following persons to be appointed as directors:

- Frank Willersinn residing [redacted]
- Maria Fernanda Aspilche-Ferro [redacted]
- Heinz Artur Dr. Stutzenberger [redacted]
- Karen Tracey Kim O'Hara [redacted]
- Cristina Emanuela Barbiero [redacted]
- Elena Goyanes Vilar residing a [redacted]

First elections of the President, the Vice-President(s), the Secretary and the Treasurer
The founding members also unanimously elect and resolve to appoint the following persons to be appointed as the following roles:

- President: Maria Fernanda Aspilche-Ferro
- Vice-President: Heinz Artur Dr. Stutzenberger
- Secretary: Karen Tracey Kim O'Hara
- Treasurer: Elena Goyanes Vilar

Proxy
The meeting decides to grant Maria Fernanda Aspilche-Ferro and Frank Willersinn, both individually empowered and with possibility of substitution, a special power of attorney, until 30 November 2023 (which can be renewed) in order to carry out the formalities with the Crossroads Bank for Enterprises, the publication in the annexes to the Belgian Official Gazette, the opening of a Belgian bank account, contacting the social services office and other administrative formalities within the framework of the incorporation of the Association and the non-statutory transitional provisions decided by the General Assembly.

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