

ARTICLES OF ASSOCIATION OF LUPUS EUROPE

Section I - Name, Office, Duration, Purposes

ARTICLE 1 - NAME

The name of the association is Lupus Europe (the “**Association**”). The Association is a non-profit association governed by the Belgian Code of Companies and Associations dated 23 March 2019 (the “**Code**”).

ARTICLE 2 - OFFICE

The registered 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 relocation does not imply a change of linguistic regime.

ARTICLE 3 - DURATION

The Association is established for an unlimited period of time.

ARTICLE 4 - PURPOSE and ACTIVITIES

4.1 The purpose of the Association is to foster the progress towards a fulfilling life for all people with lupus in Europe until a world without lupus or a cure has been reached.

4.2 The objectives of the Association is (a) that people with lupus participate in, and benefit from, lupus research, (b) that member organisations are enthusiastic and empowered and (c) that the voice of people with lupus is heard and drives action.

4.3 In furtherance of its objectives, 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 The operating area of the Association is EUROPE. For the purpose of these Articles of Association, the word “EUROPE” or “EUROPEAN” designates countries located in the geographic territory of the European continent, or that are members of the European Union (EU). The Association can also establish relationships, contacts, and partnerships with stakeholders based in other geographic areas where this is strategically appropriate for realising the purposes set out above.

4.5 The Association may engage in any activities (including of a commercial nature) to fulfil its purpose and further its objectives.

Section II - Membership

ARTICLE 5

5.1 The members of the Association shall represent self-help organisations in Europe providing support for people suffering from Systemic Lupus Erythematosus, Discoid or Cutaneous Lupus or Mixed Connective Tissue Disease.

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

1. Full Membership ("**Full Members**"); and
 2. Associate Membership ("**Associate Members**");
- (collectively, the "**Members**").

5.3 Organisations wishing to apply for Membership shall apply in writing to the Association by providing the following information:

- a letter stating that they wish to join the Association and that they accept to be bound by the provisions of the Articles of Association and the Internal Rules;
- their legal status with a certified copy of their constitutional documents;
- their permanent address including their phone number, e-mail and any other relevant details (e.g. foreign languages spoken, office hours);
- the estimated number of members or member organisations per EU member country registered in their organisation; and where they represent more disease areas, the number of members of their lupus section;
- a copy of their latest (audited) accounts.

5.4 Upon approval by the Board of Directors, applicants will be allowed to join the Association's activities and attend General Meetings as observers, with no voting rights. This will also allow for a period during which applicants and the Association better learn about each other and make a decision regarding long term membership. It is up to the Board of Directors to submit applications to the General Meeting when ready for membership approval.

5.5 Each elected organization shall be expected to offer full support to the Association.

5.6 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 Meeting in relation to the activities of the Association.

ARTICLE 6 - FULL MEMBERSHIP

6.1 The number of Full Members of the Association shall not be inferior to two (2) Full Members.

6.2 Full Membership is open to all nationally registered self-help organisations in Europe whose principal activity is to provide support for people suffering from Systemic Lupus Erythematosus, Discoid or Cutaneous Lupus or Mixed or undifferentiated Connective Tissue

Disease. Full membership is also open to lupus sections of larger patient groups that would meet the full membership adhesion criterion on their own, would they be constituted as standalone associations. Full Membership is effective upon approval by the General Meeting (in accordance with article 15.2 and 16) of the new member's inclusion as Full Member. The General Meeting does not need to justify its decision to accept or reject a member's application.

6.3 Candidates of Full Membership are required to demonstrate (i) that they are validly incorporated and registered and accepted as bona-fide organizations within their own country and (ii) their commitment to the Association's values and compliance with the following criteria, , ,:

6.3.1 Legitimacy

The Association's member organizations should be registered in EUROPE. If the applicant organization is not registered in EUROPE, additional information needs to be provided demonstrating European focus and activities. When full membership is requested by the section of a larger group, this section must have one or more representatives elected by the members of the lupus section that are designated and have the powers to validly represent them at the Lupus Europe General Meetings.

6.3.2 Democracy

The Association's Full Member organizations should have governing bodies, which are elected by their members, who may be patients, their carer, or their elected representatives.

6.3.3 Accountability and Consultation

Statements and opinions of the Association's Full Member organizations should reflect the views and opinions of their memberships and appropriate consultation procedures with those memberships should be put in place.

6.3.4 Transparency

The Association's Full Member organizations should disclose their sources of funding and provide their audited financial accounts and any document considered useful by the Association's Board of Directors in relation to all the criteria required by this article 6.

6.3.5 Continuity

The Association's Full Member organizations should demonstrate a minimum of 2 full years of existence and real activity.

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

6.3.6 Transition measure

On a transition basis, sections not meeting some of the above criterion but that are full members by 01/01/2024 shall be given a delay of three years to demonstrate meeting the criterion, absent which they will become associate members at the end of the general assembly to be held in 2027

6.4 Termination of the Full Membership status

Full Members may lose their Full Membership status and become Associate Members if one of the following event takes place: (a) upon their own request, in writing, addressed to the Secretary of the Association; (b) when they have cumulated a full 3 years of membership fee arrears, or (c) upon a decision of the General Meeting with a majority of 75% or more of the expressed votes. They will be able to regain their Full Membership status as foreseen in article 7.3, except that the waiting period of four (4) years will not apply.

6.5 Register of Full Members

The Board of Directors holds an electronic register of Full Members, which can be consulted on the website of the Association.

ARTICLE 7 - ASSOCIATE MEMBERS

7.1 Regionally or nationally registered self-help organisations in Europe providing support for people suffering from Systemic Lupus Erythematosus, Discoid Lupus or Mixed **or Undifferentiated** Connective Tissue Disease which, in the Board of Directors' opinion, do not satisfy the Full Membership criteria can apply for an Associate Membership provided they uphold the views, objectives and values of the Association. The General Meeting does not need to justify its decision to accept or reject an Associate Member's application.

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

7.3 After a period of four (4) years and once they have met the Full Membership criteria to the Board of Directors' satisfaction, Associate Members can become Full Members, subject to the General Meeting's approval. They must be nominated and seconded by two other Full Members.

7.4 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 to members.

ARTICLE 8 – CODE OF CONDUCT AND INTERNAL RULES

8.1 The Board of Directors shall prepare Internal Rules and a Code of Conduct. The Board of Directors will be competent to amend such Internal Rules and Code of Conduct, if at least half of its members are present or represented and by a majority vote of two-thirds (2/3) of the members present or represented.

8.2 Without prejudice to article 8.1, articles of the Internal Rules related to the election, removal or suspension of Board members as well as to the powers and organization of the General Meeting will have to be submitted to the General Meeting for approval.

ARTICLE 9 - ANNUAL FEE

The Members shall be required to pay an annual fee as determined by the General Meeting. The fee might vary among different groups of members or organizations. It shall not exceed EUR 1,000.

ARTICLE 10 - MEMBERSHIP SUSPENSION OR TERMINATION

Membership will be automatically suspended in case of failure to pay the due membership fee for eighteen (18) months. As a consequence, such suspended Member will not be entitled to vote at the General Meeting. The suspension will stop immediately upon payment of the membership fee due for the relevant year.

Membership may be terminated by the Member, at any time, by notifying its resignation in writing to the Board of Directors of the Association.

Membership may also be terminated by the General Meeting in case of failure to pay the Annual Fee for three (3) years (whether or not consecutive) after due notice has been given.

A Member may also be excluded from the Association in case of breach of the Code, Articles of Association, Internal Rules or if it brings the Association into disrepute. In such case, after due warning, the breach will be reported to the Board of Directors which, after investigation, will be entitled, at its sole discretion, to suspend the Member and will make a recommendation to the General Meeting as to why such Member should be expelled.

Membership may be terminated by a two-thirds (2/3) majority of the votes present or represented of the General Meeting, if at least two-thirds (2/3) of the Full Members are present or represented at the meeting. Should the Member wish to contest the decision, it shall be allowed to present its case to the General Meeting prior to the vote. Such exclusion shall be effective upon notice sent by registered letter to the president of the Member organisation.

Resigning or 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.

Section III - Voting

ARTICLE 11 - VOTING RIGHT

Only (non suspended) Full Members are entitled to vote at General Meetings.

Associate Members will have no voting rights but will have the right to participate in General Meetings.

Section IV - GENERAL MEETINGS

ARTICLE 12

The General Meeting shall consist of Full Members.

The General Meeting shall have all necessary powers required to implement the objectives of the Association, which shall include, *inter alia*:

- the establishment of a strategic plan, annual budget and working plan;
- the approval of the accounts and of the annual report of the Board of Directors ;
- the appointment and discharge of the members of the Board of Directors ;
- the amendments to the Articles of Association ;
- the appointment of an external and independent auditor;
- the dissolution of the Association and the distribution of any net assets;
- the approval of Associate and Full Members;
- the dismissal of Members ; and

- the setting of annual membership subscription rates for both Full Members and Associate Members.

ARTICLE 13

13.1 The General Meeting shall be chaired by the President (the “**Chairperson**”) or, if the President is unable to attend, by the Vice-President. If either of these parties is absent or believe they have a vested interest in a matter being debated, the chair will pass to a member of the Board of Directors.

13.2 A General Meeting shall be held annually at the latest six (6) months after the date of closing of the preceding financial year, at the registered office of the Association or at any other place as mentioned in the convening notice of the meeting. Notice of the meeting shall be given by the President at least thirty (30) days before the date of the meeting. The notice of the meeting shall indicate the date and place of the meeting as well as its agenda.

13.3 Full Members shall have the right to submit proposals for consideration by the General Meeting. They will exercise this right in accordance with the Internal Rules.

ARTICLE 14

Extraordinary General Meetings may be held on the initiative of the Board of Directors, of the Coordination Board or by a request of at least twenty percent (20%) of the Full Members. Notice of such Extraordinary General Meetings shall be given by the President at least twenty-eight (28) days before the date of the meeting. The notice of the meeting shall indicate the date and place of the meeting as well as its agenda.

ARTICLE 15

15.1 Each Full Member shall have one (1) vote at the General Meeting. Each Member shall be represented by an individual appointed by the Full Member organization. If a Member organization has a broader scope than Lupus, the representative will be a member of their lupus section. A Member may be represented by another Full Member pursuant to a written

proxy delivered to the Secretary of the Association one (1) week prior to the opening of the meeting. No person shall hold more than one proxy.

15.2 Unless otherwise provided for in the present Articles of Association or by the Code, the General Meeting shall be validly constituted and authorized to take resolutions if at least half (50%) of the Full Members are present or represented at the meeting.

15.3 If all Full Members are present or represented at the General Meeting and all are in agreement, they may modify or amend the agenda.

ARTICLE 16

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

ARTICLE 17

General Meetings can be organised in person or by tele/videoconference. Full Members may also unanimously adopt resolutions in writing.

ARTICLE 18

All Members will be informed about the decisions taken at the General Meeting. The resolutions of the General Meeting shall be recorded in minutes signed by the Chairperson and those Full Members who so wish and shall be kept at the disposal of the Members.

Section V - The Board of Directors

ARTICLE 19 – Composition and Election

19.1 Number of members and duration of the mandate

The Association shall be administered by the Board of Directors, consisting of no less than 3 persons elected by the General Meeting on proposal of The Coordination Board. It consists of at least the President, a Secretary, a Treasurer, and potentially one or more Vice-Presidents. Except for the function of President, a same person can hold 2 functions. The Secretary shall be responsible for the drafting of the minutes, the notification of the meetings that are called and the preparation of the agenda of such meetings in consultation with the President. 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 Board of Directors.

19.2 Duration of the mandate

All members of the Board of Directors shall serve for a period of three (3) years and be eligible twice for re-election (so a maximum of 9 years total).

Members of the Board of Directors may be revoked by the General Meeting at any time, by a vote of at least two-thirds (2/3) of the members present or represented. The General Meeting does not need to justify its decision.

Members of the Board of Directors may also resign at any time by notifying their resignation in writing to the Secretary of the Association, as long as such resignation is in compliance with Belgian laws.

ARTICLE 20

The President will be Chairperson of the Board of Directors and shall also be the Chairperson of the Coordination Board and the General Meeting, in accordance with Section IV of the present Articles of Association. In the event the President is unavailable, the Vice president will substitute.

ARTICLE 21

In addition to the powers specifically provided for in the present Articles of Association, the Board of Directors shall have all powers of management and administration, subject only to the powers reserved to the General Meeting. The Board of Directors will operate in accordance with the Internal Rules.

ARTICLE 22

The Board of Directors shall meet at least once a year. It shall also meet upon specific notice of its President or upon request of at least half (50%) of its members. It will meet at the time and place, and in the manner (including tele/videoconferences), of its own choosing and determine its agenda and procedures, not stated in the present Articles of Association and internal Rules.

ARTICLE 23

The Board of Directors may validly deliberate and take decisions if at least half (50%) of its members are present or represented. A resolution of the Board of Directors shall be taken by a simple majority vote of the members present or represented. In the event of a tied vote, the Chairperson of the meeting shall have a casting vote. Any Board member who cannot attend a meeting may be represented by another Board member holding a proxy.

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. The minutes shall be kept at the disposal of the members of the Board of Directors and of the General Meeting.

ARTICLE 24

In case of vacancy during a mandate, the Coordination Board shall have the power to co-opt a substitute until the next General Meeting at which such vacancy shall be formally filled.

Section VI - Support to the Board of Directors

ARTICLE 25 – The Coordination Board

25.1 Role and membership

The Coordination Board coordinates the activities and projects of the Association. It consists of the Board of Directors and additional persons elected by the General Meeting so that its total membership is no more than 7 elected persons. Persons wishing to become Board members of the Association shall send their application to the Secretary and shall be endorsed by at least one Full Member of the Association.

All members of the Coordination Board shall serve for a period of three (3) years but shall be eligible for re-election. The Coordination Board may assign titles other than President and Treasurer to some of its members.

Members of the Coordination Board may be revoked by the General Meeting at any time, for any reason that may be considered contrary to the aims or the operation of the Association, by a vote of at least two-thirds (2/3) of the members present or represented. The individual concerned shall have the right to be heard before a final decision is made unless an Ethics committee composed as per the Internal Rules decides that such hearing by the General Meeting would expose other individuals to unfair treatment, or breach of confidentiality in a significant way.

Members of the Coordination Board may also resign at any time by notifying their resignation in writing to the Secretary of the Association. In case of vacancy during a mandate, the other Board members shall have the power to co-opt a substitute until the next General Meeting at which such vacancy shall be formally filled.

25.2 Meetings

The Coordination Board shall meet at least once a year. It shall also meet upon specific notice of its President or upon request of at least half (50%) of its members. It will meet at the time and place, and in the manner (including tele/videoconferences), of its own choosing and determine its agenda and procedures, not stated in the present Articles of Association and internal Rules.

The Coordination Board may validly deliberate and take decisions if at least half (50%) of its members are present or represented. A resolution of the Coordination Board shall be taken by a simple majority vote of the members present or represented. In the event of a tied vote, the Chairperson of the meeting shall have a casting vote. Any Board member who cannot attend a meeting may be represented by another Board member holding a proxy.

ARTICLE 26 – Medical Board

The Coordination Board shall appoint a board of leading internationally recognized European Doctors specialized in Lupus or Lupus relevant matters, to advise the Association on medical questions and to help promote the voice of patients in scientific events. The medical board membership will be reviewed on a 3 to 5 years basis to ensure best talents are included, but prolonged membership will be encouraged.

ARTICLE 27 – Advisors and working groups

The Coordination Board may on an annual basis, appoint special advisors for specific projects or associated board members, who might be invited to attend Coordination Board meetings, but will not have voting rights.

The Coordination Board may also form 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 28 – General Secretariat

The Board of Directors may appoint, after consultation with the Coordination Board, a General Secretary to support the on-going operations of the Association. The General Secretary 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. The General Secretary may be revoked at any time by the Board of Directors by simple majority of the votes present or represented. The General Secretary will support the President, Vice-President, Secretary and Treasurer Chair, in their responsibilities. It may 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, organize 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.

The Board of Directors may also appoint, after consultation with the Coordination Board, any other person to support the organization in any given particular area and provide it with appropriate powers to represent, negotiate, organize 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.

Section VII - Budget and Account

ARTICLE 29

The financial year shall be the calendar year ending on 31 December (the “**Financial Year**”).

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

The annual accounts and supporting documentation will be open for inspection by the Members and a summary will be available on the Association’s website.

The Treasurer will present a financial statement to the Board of Directors at each meeting.

Section VIII - Representation of the Association

ARTICLE 30

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, by the General Secretary, or by a person (Board member or not) specifically appointed by the Board of Directors (proxyholder).

Except in case of a special proxy holder, all documents signed on behalf of the Association shall be binding for the Association when signed by the President, who will not have to justify to third parties his/her signatory powers.

The Board of Directors may delegate the day-to-day management of the Association to a General Secretary, a person of its choice, or other officers.

Section IX - Amendment of the Articles of Association and dissolution

ARTICLE 31

A proposal dealing with an amendment of the present Articles of Association or the dissolution of the Association shall be initiated by the Board of Directors or from at least one fifth (1/5) of the members of the Association.

Except in the case of an emergency, the Board of Directors shall give at least thirty (30) days' prior notice to the members of the Association of the date of the Extraordinary General Meeting, which shall deal with the said proposal as well as of the details of such proposal.

The Extraordinary General Meeting may deliberate and decide validly only if two-thirds (2/3) of all Full Members of the Association are present or represented; any resolution to amend the present Articles of Association must be adopted by a majority of four-fifths (4/5) of the votes cast for an amendment to the purpose of the Association and of two-thirds (2/3) of the votes cast for all other amendments.

If the above-mentioned two-thirds attendance quorum is not reached, a new Extraordinary General Meeting shall be convened in accordance with the conditions outlined above. 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.

The General Meeting shall determine the manner of dissolution and liquidation of the Association, which shall be decided by a majority of four-fifths (4/5) of the votes cast. 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 General Meeting on the use of such liquidation proceeds, the residual amount will be transferred to EULAR –PARE (European League Against Rheumatism – Patients Against Rheumatism in Europe) (or if it no longer exists to its successor organization).

Section X - General Provisions

ARTICLE 32

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.

ARTICLE 33

The text of the present Articles of Association shall exist in English and in French. In case of disagreement between the two texts, the French text ("*Statuts*") will prevail and be binding.