

LUPUS EUROPE CONSTITUTION - AS APPROVED BY GENERAL ASSEMBLY 2017

1. NAME

1.1 The name of the Association shall be : LUPUS EUROPE

2. OBJECTS

2.1 The objects of LUPUS EUROPE are the advancement of public education concerning all aspects of Lupus both in the medical and sociological areas of the disease.

3. AIMS AND POWERS

3.1 To collect information on all aspects of Lupus, both in the medical and sociological areas of the disease.

3.2 To assist in improving knowledge of the disease for people with Lupus and for members of the health, welfare and medical professions.

3.3 To encourage and/or undertake surveys and research projects related to the disease and the publication of the useful results of any such research.

3.4 To promote awareness of the disease throughout Europe and the Support Groups that are available for sufferers in each member country.

3.5 To sponsor and/or promote European symposia on all aspects of Lupus.

3.6 To gain representation on any European or international body whose interests could be of benefit to members of LUPUS EUROPE.

3.7 To assist with the establishment of Support Groups in other European countries where at present they do not exist.

3.8 To promote all such other lawful actions as are necessary for the attainment of the above objects.

4. MEMBERSHIP

4.1.1 Full (voting) membership of LUPUS EUROPE is open to all nationally registered self-help organisations in Europe providing support for people suffering from Systemic Lupus Erythematosus, Discoid Lupus or Mixed Connective Tissue Disease. Election of full member organisations shall take place at meetings of Council.

4.1.2 Associate (non-voting) membership of LUPUS EUROPE is open to additional regionally or nationally registered self-help organisations in Europe providing support for people suffering from Systemic Lupus Erythematosus, Discoid Lupus or Mixed Connective Tissue Disease. Election of associate organisations shall take place at meetings of Council and Council may exercise the right to ask the applicant organisation to attend a first Convention as an observer.

4.1.3 Following four years as Associate (non-voting) members of LUPUS EUROPE, nationally registered organisations may apply to Council for full (voting) membership having been nominated and seconded by two other full (voting) member organisations. Associate regionally registered organisations shall remain non-voting.

Art 4.1.4: Full (voting) members will lose their full membership status and become Associate members after one of the following event has taken place: (a) upon their own request, in writing, addressed to the secretary; (b) when they have cumulated a full 3 years of membership fee arrears, or (c) upon voting of the council (or special meeting), with a majority of 75% or more of the expressed votes. They will be able to regain full voting membership status as foreseen in article 4.1.3, except that the waiting period of 4 years will not apply.

4.2 Each organisation prior to election shall be required to satisfy the Trustees that they are correctly set up and accepted as bona-fide organisations within their own country.

4.3 Each elected organisation shall be entitled to send a delegation of two people to Conventions and

other appropriate meetings.

4.4 At all meetings, each full membership nationally registered organisation, having paid the set annual subscription, shall be allowed one vote.

4.5 Each elected organisation shall be expected to offer full support to LUPUS EUROPE.

4.6 At all meetings, delegates must have full powers to make decisions on behalf of their own organisation Management Board/Trustees.

5. COUNCIL

5.1 The overall control of LUPUS EUROPE shall be administered by Council.

5.2 One nominated delegate from each full voting member organisation shall serve on Council and shall carry one vote. Each Trustee shall also serve on Council and shall carry one vote.

5.3 Council meetings shall occur at every Convention which shall take place at least once in every twenty-four months and for which the Secretary shall give notice of at least 56 days.

5.4 Council shall set annual membership subscription rates for both full and associate member organisations.

5.5 Decisions of Council shall be accepted on a majority of one except where voting takes place at Special Meetings, on Amendments to the Constitution, on Dissolution or on removal of a Trustee.

5.6. The quorum at meetings of Council shall be one half the voting membership and must include one elected officer.

6. TRUSTEES

6.1 The general administration of LUPUS EUROPE shall be undertaken by the trustees.

6.2 The Trustees shall be elected by Council, shall hold office for three years and shall be eligible for re-election on a rotational (three-year) basis. Their number will not exceed 6.

6.3 At their first board meeting after election, the Trustees shall elect amongst themselves the Chairperson, Vice-Chairperson, Secretary and Treasurer.

6.4 Candidates to the election as Trustees will send their application to the Secretary, endorsed by a Full (voting) member of LUPUS EUROPE. The Secretary shall circulate the names of all nominees to each full member organization 28 days prior to the Elections.

6.5 If at any time after the election of the Trustees a vacancy should arise the remaining Trustee members shall, at their discretion, appoint a replacement member whose appointment shall be approved at the next meeting of Council or Special Meeting. Such replacement trustees will not have voting rights until their appointment is ratified by the convention or a special meeting.

6.6 A Trustee may be removed from office by 2/3rds majority vote of Council at any time for any reason that may be considered contrary to the aims or the operation of LUPUS EUROPE provided that the individual concerned shall have the right to be heard before a final decision is made.

6.7 A Trustee may resign at any time by giving written notice to LUPUS EUROPE through the Secretary.

6.8 The Chairperson, or in his/her absence the Vice-Chairperson, shall conduct meetings of both the Trustees and Council and shall be responsible for the taking of any urgent action between meetings of the Trustees or Council.

6.9 The Secretary shall be responsible for the minutes, the notification of such meetings that are called and the preparation of the Agenda in consultation with the Chairperson and all correspondence in connection with meetings of the Trustees and Council.

6.10 The Treasurer shall be responsible for the proper management of the central funds, for receiving dues and contributions on behalf of LUPUS EUROPE, the publication of accounts and the recommendation of Auditors to the Trustees.

6.11: The quorum at meetings of the Trustees shall be 2/3rd of the trustees.

7. SUPPORT TO THE BOARD

7.1 The Trustees may, on an annual basis, co-opt Advisors for specific projects, these Advisors shall be non-voting.

7.2 The board shall appoint a board of leading internationally recognized European Doctors specialized in Lupus or Lupus relevant matters, to advise LUPUS EUROPE on medical questions and to help promote patient voice 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.

7.3 The board may appoint a General Secretary to support the on-going operations of LUPUS EUROPE. The General Secretary will report to the board, and attend Board meetings (with exceptions of sessions that would result in a conflict of interest), but with no voting rights. The General secretary may be revoked at any time by the board by simple majority. If revoked, terms of termination will be handled based on applicable contractual/employment law.

7.4 The General Secretary will support the Chair, Vice-Chair, Secretary and Treasurer in their responsibilities per articles 6.8 to 6.10 of this constitution, and all trustees on the running of their responsibilities without removing or eroding the ultimate responsibilities of trustees

7.5 The General Secretary may make any proposals to the board with regards to the operation of LUPUS EUROPE, its strategies, projects, budgets, meetings or others; it being understood that the decision right remains with the board and the council.

7.6 The General Secretary may represent, negotiate, organize and sign on behalf of LUPUS EUROPE any agreements, reports, applications, representations or others deemed necessary for the proper operation of LUPUS EUROPE, in line with decisions made by the board.

7.7 If urgent action is required beyond existing board decision, the General Secretary will seek approval of the Chair based on art 6.8 of this constitution, or of a majority of Trustees through a board meeting or consultation.

8. SPECIAL MEETINGS

8.1 A Special Meeting may be called by two or more Trustees and/or Council Members by writing to the Secretary.

8.2 The Secretary shall then call a Special Meeting by giving member organisations at least 28 days notice of the Meeting where the Agenda shall comprise only of the business item giving rise to the calling of the Meeting. If appropriate, the invitation will include the specific questions that will be submitted to vote during the meeting, as well as the voting forms that will be used.

8.3 Voting at special meeting shall be allowed not only by members physically present, but also by proxy or, to the extent possible, by mail. Voting at a Special Meeting shall require the agreement of 2/3rds of the total Trustees, members present and entitled to vote, proxy holders and votes carried by mail.

8.4 To vote by proxy, member organizations shall submit a letter signed by the organization's president in which they clearly state the organization or person that will vote on their behalf. This letter must be sent to the secretary at least 1 week prior to the special meeting date. The exact names and address where the letter must be sent will be clarified in the invitation. Each person present at the meeting will only be allowed to represent one other member.

8.5 To vote by mail, member organizations shall use the voting form sent with the invitation to the special meeting. This completed form shall be put in a sealed envelope that will only carry the organization name and country and the signature of the organization's president. This envelope will be sent together with a letter signed by the organization's president confirming its desire to vote by mail. This letter must be sent to the secretary at least 1 week prior to the special meeting date. The exact names and address where the letter must be sent will be clarified in the invitation.

8.6 Before the voting, the secretary will announce the names of the organizations that have voted by mail, and show the unopened envelopes. The Secretary will then request holders of proxy to identify the

organizations they have a proxy from and verify their credentials. If an organization has both a vote by mail and a proxy holder, the vote by mail will be discarded. Proxy and mail votes from members that have not paid their annual membership will be discarded. The remaining valid envelopes will be opened and the mailed voting sheet will be put in the ballot box.

9. AMENDMENT TO THE CONSTITUTION

9.1 A Resolution of Amendment to the Constitution must be received by the Secretary at least 35 days before the Council or Special Meeting.

9.2 At least 28 days notice of the Meeting must be given by the Secretary to full member organisations and must include details of the alteration(s) proposed.

9.3 Alteration of the Constitution shall require the agreement of 2/3rds of the total Trustees and members present and entitled to vote.

9.4 Provided that no alteration shall be made to Clause 2 (Objects), Clause 9 (Dissolution) or this Clause until approval in writing of the United Kingdom Charity Commissioners or other authority having charitable jurisdiction shall have been obtained and no alteration shall be made which would have the effect of causing LUPUS EUROPE to cease to be a charity in law.

10. DISSOLUTION

10.1 LUPUS EUROPE may be dissolved by a Resolution passed by 2/3rds majority of those present and entitled to vote at a Council Meeting or Special Meeting convened for the purpose of which 28 days notice shall have been given by the Secretary to member organisations.

10.2 Such Resolution shall give instructions for the disposal of any assets held by or in the name of LUPUS EUROPE, provided that if any property remains after the satisfaction of all debts and liabilities such property shall not be paid to or distributed among the members of LUPUS EUROPE but shall be given or transferred to such other charitable institution or Institutions having objects similar to some or all of the objects of LUPUS EUROPE as LUPUS EUROPE may determine and if in so far as effect cannot be given to this provision then to some other charitable purpose.

Amendments to LUPUS EUROPE Constitution agreed by council in Milan on November 20, 2017