

# Agora



Platform of Organisations  
of people with Rheumatic Diseases  
in Southern Europe

## AGORA BYLAWS

Updated and approved during the Agora General Assembly:

22 September 2017

## **1 NAME**

1.1 The name of the organization shall be Agora and is hereinafter referred to as Agora. It is a non-governmental, non profit organization registered in Greece, Athens with the code [insert code number]

## **2 AIMS**

2.1 Provide member organizations representing people with Rheumatic and Musculoskeletal Diseases (RMDs) both in Southern Europe and borders and other peer user-led organizations that fall outside the Southern area (Eastern, Western and Northern Europe and generally within the area of Europe) with a stronger voice at a national and European level (please advice Appendix 3 for special conditions which apply to countries that fall outside of the geographical area of Southern Europe). The character of AGORA remains the same and focuses on working towards creating better conditions for people with RMDs in Southern European countries, despite giving the opportunity to countries that fall outside this geographical area to join the organization.

2.2 Encourage and assist in the foundation and development towards user-led organizations of people with rheumatic and musculoskeletal diseases in Southern Europe;

2.3 Promote supportive attitudes towards rheumatic and musculoskeletal diseases and enable patients to live independent and participate fully in society.

## **3 OBJECTIVES**

3.1 Establish and promote a common agenda for health and advocacy for people with rheumatic and musculoskeletal diseases in Southern Europe and other areas (if the case) outside Southern Europe (special conditions apply to countries outside Southern Europe); the specific goals would be to reduce the burden of RMDs on the individual and society, to support the rights of people with RMDs to high quality information, education, care, treatment, rehabilitation, prevention and independent daily living, representing the interests of entire RMD community on European and national level.

3.2 Collect and distribute information on all aspects of rheumatic and musculoskeletal diseases, both in the medical and sociological areas of the disease.

3.3 Foster innovation and excellence in education and research with the aim to improve treatment and patient care.

3.4 Assist in improving the knowledge of rheumatic and musculoskeletal diseases among

members of the health, welfare and medical professions, governmental bodies and the general public.

3.5 Encourage and undertake research projects including surveys and clinical trials related to rheumatic and musculoskeletal diseases and dissemination of the results of any such research.

## **4 MEMBERSHIP**

4.1 Membership of the Agora is open to patient organizations from Southern European countries as defined by geographical criteria and according to the United Nations classification, providing support for people with rheumatic and musculoskeletal diseases. (See appendix 1) The annual fee for membership is 50 Euros.

4.2 The Agora membership is divided into two categories:

- a) Full memberships: Full Agora memberships will be awarded to patient organizations which are in complete compliance with Agora's Bylaws, aims and objectives and are classified as Southern European countries, as defined by geographical criteria and according to the United Nations classification.
- b) Co-opted memberships: Co-opted memberships will be awarded to patient organizations which are in complete compliance with Agora's Bylaws, aims and objectives, but are not classified Southern European countries, as defined by geographical criteria and according to the United Nations classification.

4.3 Membership of Agora is also open to patient organizations originating from countries that fall outside Southern Europe according to the United Nations classification; Agora will henceforth accept organizations that belong to this category as co-opted members. These organizations may be regional or national. This category of organizations will be accepted as Agora members under special conditions and will have restricted rights in the General Assembly meetings, as well as no voting rights. Agora Board will discuss the potential candidates and nominate the potential co-opted members to the General Assembly during the annual meetings. If the General Assembly does accept the candidate organization to become a co-opted member, the secretariat will provide an official letter of invitation. The annual fee for co-opted membership is 30 Euros.

The annual AGORA Conference is open for participation by co-opted members up to one representative. The costs of participation will be fully reimbursed. Co-opted members will not have the right to host the Annual Agora Conference in their country.

Regular communication between AGORA and its member organizations is vital for achieving the aims and objectives on national and European level. Member organizations (full and co-opted) are asked to designate a liaison person who will act as the main contact for AGORA and the secretariat (for more see Appendix 4). Depending on the type of information or request the liaison person will share the message with the relevant people in the member organization as needed.

## **5 GENERAL ASSEMBLY (Membership Assembly)**

5.1 The General Assembly consists of all member organizations of people with rheumatic and musculoskeletal diseases in Southern Europe.

5.2 The General Assembly is the highest decision-making body of Agora.

5.3 The General Assembly will be held once a year.

5.4 Each member is entitled to send a delegation to the annual General Assembly.

5.5 At the General Assembly each member is entitled to one vote, with the exception of the co-opted members, who will have the right to contribute in the General Assembly discussion strictly as observers, but will have no right to participate in the voting procedure (for more information on co-opted memberships and their rights and responsibilities, please see Appendix 3)

5.6 At the General Assembly the delegation should have full power to make decisions on behalf of their organization.

5.7 Approval of the annual budget will require a two-thirds' majority vote. All other decisions will be accepted on a majority vote of one.

5.8 The General Assembly is entitled to decide which organization will be a member according to the specifications of Appendix 1.

5.9 A special session of the General Assembly can be called by one third of the members of Agora or by the Board.

## **6 ADMINISTRATION**

6.1 The overall control of the organization will be administered by a Board of five persons who are elected by the member organizations of Agora during the General Assembly (see Appendix 2 for the nomination and electoral procedures). The work done by the Board members is voluntary work. They should meet the recommended criteria, including skills and experiences according to Appendix 2. The Board also acts as a “think-tank” developing patient perspectives and views.

6.2 The Agora Board is responsible for the everyday management of the organization. Part of the responsibility is the organization of the General Assembly, at least once a year, and the development of proposals for voting and election procedures to the General Assembly, such as Agora membership criteria, voting procedures for the General Assembly and Terms of Engagement for Agora Board members. The Chair must present a report on activities to the General Assembly every year.

6.3 All the members of the Board will serve a period of three years. They will be eligible for re-election according to the Agora's Bylaws Appendix 2 but no more than two consecutive terms of office (namely 6 consecutive years).

6.4 The Board will elect among themselves a Chairperson, a General Secretary (who will act as Vice-Chairperson in the absence of the chair), and a Treasurer. The two remaining elected candidates will serve as members of the Agora Board.

6.5 The Board may decide on the appointment of dedicated staff persons who assist in the daily work of the Board and provide administrative and secretarial support or project management.

6.6 The Secretariat will:

6.6.1 Be the custodian of the records of the organization.

6.6.2 Maintain record books in which official acts of the organization are entered along with any amendments.

6.6.3 Perform such other duties as may be determined from time to time by the Board.

6.6.4 Be responsible for all secretariat work and the correspondence of the organization.

6.7 The Treasurer shall receive contributions and prepare annual reports on behalf of the organization.

6.8 Board member(s) may resign at any time by giving written notice to the organization. Any such resignation shall take effect upon the date of the receipt of such notice or at any later time specified therein.

6.9 The Board must authorise any expenditure that comes outside the budget approved by the previous Board Meeting and in case of urgent cases the Treasurer and the Chair will be given the permission to act accordingly. Members should be notified of these decisions.

6.10 If necessary the Board may appoint an auditor to report to the General Assembly.

## **7 ALTERATION OF BY LAWS**

7.1 Alteration to these By-laws shall receive the assent of the two-thirds of the Agora General Assembly. A resolution of the alteration of the By-laws must be received by the General-Secretary of the Agora Board at least 21 days before the General Assembly meeting at which the resolution is to be brought forward. At least 30 days' notice of such a meeting must be given by the Chair of the Agora Board to all Agora members, and should include full information regarding the alterations

## **8 DISSOLUTION**

8.1 Agora may be dissolved by a resolution passed by a two-thirds majority of those present and voting at a Special Session of the General Assembly convened for the purpose of which 21 days' notice is given to all Agora members. Such resolution may give instructions for the disposal of any assets held by or in the name of the Agora, 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 the Agora but shall be given or transferred to such other charitable institution or institutions having objectives similar to some or all of the objectives of the Agora as the Agora may determine and if and in so far as effect cannot be given to this provision then to some other charitable purpose

These Bylaws were approved at a meeting held in Zagreb, on the 22<sup>nd</sup> of September 2017 by delegates representing Southern European Patient Organizations of people with Rheumatic and Musculoskeletal Diseases from the following countries:

1. Bulgarian Organization for Patients with Rheumatology Diseases
2. Croatian League Against Rheumatism
3. Cyprus League Against Rheumatism
4. Hellenic League Against Rheumatism
5. Association of Patients with Rheumatic Disease of Crete
6. Arthritis and Rheumatism Association Malta
7. Romanian League Against Rheumatism
8. Association of Rheumatic Diseases Patients of the Republic of Serbia
9. National Coordinator of Arthritis (Spain)
10. APMAR
11. Catalan Rheumatologic League
12. ACS France
13. Montenegro

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## *APPENDIX 1*

### **FULL MEMBERSHIP CRITERIA**

## Full Agora membership criteria

- 2.1 Full Agora member organizations should be non-profit and non-governmental organizations.
  - 2.1.1 Any applying organisation/association must be in position to prove their non-profit and non-governmental status by providing official documentation (translated in English if in other language).
  - 2.1.2 The term non-profit refers to a “non-business entity”, which entails that the members of this organisation formed an entity in order to "to pursue a common not-for-profit goal, that is, to pursue a stated goal without the intention of distributing excess revenue to members or leaders"<sup>1</sup>.
  - 2.1.3 All organisations/associations which apply for an Agora membership, should be able to prove that they have no business or financial activity by means of profit making. This may entail the provision of official documentation from the state and/or bank statements.
  - 2.1.4 In the case that an organisation can carry out any business or financial activities within the country of origin, the Agora Bylaws and regulations may overrule the national legislation. In such incidents, the Agora Board may have the right to submit a decision regarding the membership in question for the vote of the General Assembly.
- 2.2 Full Agora member organizations should be national or regional ones.
- 2.3 Organizations should represent rheumatic and musculoskeletal diseases.
- 2.4 They should be proven active on national level or regional level.
- 2.5 They should have shown an active contribution to previous Agora projects.

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<sup>1</sup> Smith, David Horton; Stebbins, Robert A.; Dover, Michael A. (2006). *A Dictionary of Nonprofit Terms and Concepts*. Bloomington: Indiana University Press. ISBN9780253347831. p. 156-157 ("nonprofit group"); p. 158-159 ("nonprofit organization").



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## *APPENDIX 2*

### **ELECTION, NOMINATION PROCEDURES AND CRITERIA FOR BOARD MEMBERS- REQUIREMENTS AND DUTIES**

## **Agora Board members**

### **Election procedure and requirements for skills and circumstances of Board Members**

#### **2.1 Nomination procedure**

2.1.2 Each Agora full member-association is entitled to nominate **only one** candidate-representative, who should be an official and approved member of the member-association and should be a patient with rheumatic and musculoskeletal diseases.

2.1.3 The nominated candidate(s) must be official and approved member(s) of the full Agora-member association for at least one year prior to his/her nomination, during the election process and throughout the term of office at the Agora Board, and for at least 6 months following his/her dismissal from the Agora Board or the end of his/her term of office.

2.1.4 The nominated candidate must be an adult (18 years old and up).

2.1.5 In the exceptional case where more than one nominated candidates originate from the same country:

2.1.5.1 The concerned member-associations are requested to conduct an internal election which will result to **one joint nomination** representing the country of origin, so to avoid parity voting.

2.1.5.2 In the event of noncompliance, the objecting full member-association should provide a statement to support the objection to the Agora Board. If the Agora Board cannot resolve the issue, the matter will become subject to vote during the General Assembly, which will decide upon the objecting association's candidacy.

2.1.6 Candidate full-members in trial period can nominate a candidate for the elections, regardless of their status as candidate members on trial period. Nevertheless, full candidate members may only participate to the election procedure once the General Assembly has ratified their membership during the annual General Assembly meeting, which takes place before the elections.

#### **2.2 Requirements of eligible candidates**

2.2.1 The candidate should be officially nominated by the organisation of people with rheumatic and musculoskeletal diseases, which must be a full member of Agora.

2.2.1.1 The nominated candidate(s) must be official and approved member(s) of the full Agora-member association for at least one year prior to his/her nomination, during the election process and throughout the term of office

at the Agora Board, and for at least 6 months following his/her dismissal from the Agora Board or the end of his/her term of office.

- 2.2.2 All Agora full member-associations have the right to participate to the Agora Board elections.
  - 2.2.2.1 Each Agora full member-association is entitled to nominate **only one** candidate-representative, who should be an official and approved member of the member-association.
  - 2.2.2.2 The candidate must have personal experience of living with a rheumatic disease (namely be a patient himself/herself).
- 2.2.3 Provided that Agora is a patient-led organization by regulation, health professionals, support staff and informal care-takers do not have the right to be nominated as candidate-representatives in the Agora elections.
- 2.2.4 All candidate full-members during trial period may nominate a candidate for the elections, regardless of their status as candidate members during trial period. Nevertheless, candidate full-members **may only** participate to the election procedure once the General Assembly has ratified their membership during the annual General Assembly meeting, which should take place before the elections.
- 2.2.5 Co-opted members do not have the right to participate with a nomination nor have the right to vote during the Agora elections (see Appendix 3).
- 2.2.6 The candidate should be actively involved in the national organisation or regional organization of his/her country, with experience in different fields of its work and if possible in the international area.
- 2.2.7 In the exceptional case where more than one nominated candidates originate from the same country:
  - 2.2.7.1 The concerned member-associations are requested to conduct an internal election which will result to **one joint nomination** representing the country of origin, so to avoid parity voting.
  - 2.2.7.2 In the event of noncompliance, the objecting full member-association should provide a statement to support the objection to the Agora Board. If the Agora Board cannot resolve the issue, the matter will become subject of voting during the General Assembly, which will decide upon the objecting association's candidacy.
- 2.2.8 The candidate should have internet access or at least regular access to these communication systems.
- 2.2.9 Candidates and Board members should not be working for pharmaceutical companies and other potential sponsors, occupy public offices or be members of political parties at a leading level because this situation could lead to conflict of interest.

## 2.2 Skills

- 2.2.1 To facilitate the communication between the Board members and other bodies a good oral and written working knowledge of English is required.
- 2.2.2 Able to work in a team, and to take actively responsibility for certain working areas within the Board.

- 2.2.3 Able to operate strategically.
- 2.2.4 Presentation and negotiation skills.\*

\*These skills are essential for the Chair.

### **2.3 Electoral procedure (rules and regulations)**

- 2.3.1 Agora Board members are elected by Agora members for a period of three years unless a board member resigns before the expiration of his/her term. In this case Agora members will elect a new person. Voting process in such an extraordinary case can be done also via email.
- 2.3.2 Each full member association is entitled to one vote during the General Assembly.
- 2.3.3 During exceptional cases of member associations originating from the same country, a vote may only be valid on the basis of the rule “one country, one vote”. The member-associations will have the right to confer for 10 minutes during the General Assembly to agree on their vote. In the case where a common decision is not taken, the vote of the member-associations (as per country) may not be valid and counted in the voting procedure.

### **2.4 Duties**

- 2.4.1 Participation at the Board Meetings (physical or via phone/Skype) and General Assembly.
- 2.4.2 Correspondence is done by email or tele-calls.
- 2.4.3 Willingness and ability to attend project meetings within a core group and events the Board organises with third parties.
- 2.4.4 The Chair’s specific duties:
  - 2.4.4.1 The Chair is required to represent the organisation during official events (upon invitation) and lead the discussions and negotiations with the purpose of accumulating funds and grants for the organisation.
  - 2.4.4.2 The Chair is required to maintain the contacts with partners (financial supporters and providers) and make them available to the Secretariat and to the next Chair.
  - 2.4.4.3 The departing Chair is required to serve for another year following the end of his/her term as an advisor to the newly elected Agora Board. The departing Chair may offer advice to the Board and may be called to attend a Board meeting if required or requested by the Board, nevertheless, without having any acting authority. The departing Chair is required to participate as a member in the Task Force for the preparation of the next Annual Agora Conference.
- 2.4.5 Financial duties:
  - 2.4.5.1 The Chair and Treasurer are the **only** authorised administrators of the Agora bank account. Any transaction from the Agora account can only be authorised by the Chair and Treasurer with the provision of two signatures.

- 2.4.5.2 A designated member of the Secretariat may have access to the Agora bank account to assist the Chair and Treasurer in placing payments, nevertheless transactions can only be carried out with the authorisation of both the Chair and the Treasurer.
- 2.4.5.3 The Chair and Treasurer have the duty of approving and authorising any transfer from the Agora account related to the organisation's expenses.
- 2.4.5.4 The Chair and Treasurer do not have the right to use or extract funds from the Agora account to cover personal expenses unrelated to Agora activities.
- 2.4.5.5 The departing Chair and Treasurer are required to continue their duties related to the financial procedures and activities (namely for bank transfer authorisations) up to 3-6 months following the end of their term of office, until all the official procedures regarding the transfer of access and rights to the Agora Bank account to the newly elected Chair and Treasurer have been arranged by the Secretariat.

**Note:** In principle, the time Board members spend on Agora activities is not reimbursed. Costs for travel, accommodation and meals may be reimbursed. These rules have been developed to enable volunteers from member organizations of people with rheumatic and musculoskeletal disease with a difficult financial background to become a member of the Agora Board and to prevent these potential financial difficulties hinder those to become active, who otherwise might have joined.

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# *APPENDIX 3*

## **CO-OPTED MEMBERSHIPS CRITERIA**

## **Co-opted memberships admission criteria**

The criteria considered for selecting the organizations as co-opted members would be as follows:

- 3.1 Agora co-opted member organizations should be non-profit and nongovernmental organizations, which fall outside the geographical area of Southern Europe and borders.
- 3.2 Agora co-opted member organizations should be national or regional ones.
- 3.3 Agora co-opted member organizations should represent all / or more than two rheumatic and musculoskeletal diseases.
- 3.4 The co-opted members will have restricted rights and will be excluded from any voting procedures.
- 3.5 Agora co-opted members will have the right to attend the General Assembly and contribute in the discussions, however they will not bear the right of vote.
- 3.6 Co-opted members should be proven active on national level or regional level.
- 3.7 They should have shown an active contribution to previous Agora projects. The co-option candidates need to have shown an active involvement/contribution in AGORA's activities and projects, and/or the Task Force and/or participated in the European lobby for the interests of all people with RMD's.
- 3.8 Co-opted members' representatives will not have the right to become Board members nor participate to the election procedure as candidates or voters, as a consequence of their limited voting and decision-making rights.
- 3.9 The co-opted membership will have a term of three years. The AGORA BOARD will then evaluate the membership and if positive the co-option could be prolonged for another period.
- 3.10 Agora has the right to amend or alter any of the above terms and criteria concerning co-opted memberships.
- 3.11 All co-opted members will be offered the following opportunities:
  - 3.11.1 Participation to the General Assembly meetings and discussions
  - 3.11.2 Participation to Task Force groups
  - 3.11.3 Participation to the AGORA Annual Conference program and dinner
  - 3.11.4 Access to AGORA Annual Conference report
  - 3.11.5 Information about all the AGORA activities
  - 3.11.6 Access to all the AGORA projects and tools
  - 3.11.7 Access to the AGORA network

### **3.12 Term of membership**

The co-opted membership will have a membership term of three years. The AGORA BOARD will then evaluate the membership and if positive the co-option could be prolonged for another period.

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# *APPENDIX 4*

## **ROLE DESCRIPTION OF A MEMBER ORGANISATION'S LIAISON PERSON**



## **Role description of the liaison person**

- 4.1 Liaison person is defined as the contact point between a member organization and Agora.
- 4.2 The liaison person will handle all the communications between the member patient organization he/she is representing and Agora. The communication may be regarding the participation of the organization in the Annual Agora Conference, the participation in Agora's activities and projects, the briefing on the activities of this organization, the settlement of the annual membership fee, and other necessary communication that ensures the orderly conduct of Agora's activities.
- 4.3 The liaison may be in direct contact with the Agora Secretariat.
- 4.4 The liaison person may be the Secretariat of the member organization or a person that is specifically assigned the role of the liaison person by the board of the member organization.
- 4.5 In case the liaison person is changed for any reason, the member organization is obliged to notify Agora in due time and introduce a replacement liaison in a reasonable period of time.