



ANIRIDIA EUROPE

***Comments and recommendations
by the Board of Directors
on the proposals for amendments
to the Statutes of Aniridia Europe***

Notice

In black: original text and proposal of amendments

In blue: comments and recommendations by the Board of Directors on the proposed amendments

a) Proposal for amendments to Art. 5 and its sub-articles of the Statutes of Aniridia Europe

Presented by the French association Gêneris, full member of Aniridia Europe, according to the provisions of Art. 6: *Change of these Statutes*, and to be submitted to the General assembly, that will be held in Duisburg on August 26th, 2016

1. Proposal to agenda for the General Assembly (hereafter GA) 2016 from Association GENIRIS. Revision of statutes article 5.1. The original text “Aniridia Europe is administered by a Board of Directors composed of 4 to 9 Members, elected by the General Assembly by the Members of the Federation” is to be replaced by the following text: “Aniridia Europe is administered by a Board of Directors composed at least of 4 Members, elected by the General Assembly by the Members of the Federation.”

Comments

- The Board of Directors is an executive organ that requires a limited number of persons to work properly;
- Removing the upper limit would result in an indefinite number of persons elected, which would create less effectiveness, smoothness and rapidity in the procedures;
- See also comments to art. 5.3.1

Recommendations

The Board of Directors unanimously recommends that General Assembly vote against the proposal

2. Proposal to agenda for the GA 2016 from Association GENIRIS. Revision of statutes article 5.1. The original text “Each Member Association can have no more than one seat on the Board.” is to be replaced by the following text: “Each Member Association can have at least one seat on the Board by country, 2 seat by big European countries.”

Comments

- The formulation is unclear and open to misunderstandings because “at least” means that there is no limit of seats for any country, no matter if small or big, with the consequences already seen under the previous point;
- The definition of “big countries” is not clear; which is the parameter? population, GDP, level of welfare, number of patients...? Without having defined what a “big” country is, this proposal is simply inapplicable and could lead to controversies;
- See also comments on art. 5.3.1

Recommendations

The Board of Directors unanimously recommends that General Assembly vote against the proposal

3. Proposal to agenda for the GA 2016 from Association GENIRIS. Revision of statutes article 5.3.1. The original text “The Board of Directors is composed of 4 to 9 Members, elected by the General Assembly by the Members of the Federation” is to be replaced by the following text: “The Board of Directors is composed at least of 4 Members, elected by the General Assembly by the Members of the Federation. The number of members of Board must be balanced by country and maybe by size of country : at least 1 member by country, 2 member by big European countries.”

Comments

- The Board of Directors is an executive organ that acts on a mandate by the General Assembly. Its members do not represent their own countries, but the aniridia community as a whole, and the requirement for their election is not their nationality, but that they are considered committed, loyal to AE principles and fit for the task;
- The need of geographical representativeness is fulfilled by the General Assembly, which is the supreme organ of the federation. Each full member association is correctly represented inside the General

Assembly and there is no need for a geographical balance inside the Board of Directors;

- As already said, the definition of “big countries” is not clear; which is the parameter? population, GDP, level of welfare, number of patients...? Without having defined what a “big” country is, this proposal is simply inapplicable and could lead to controversies;
- The same idea of giving more weight to a country based on its size is contradictory in respect to the fact that we are a RD federation. By definition, we do not think that “smaller” means “less important”, and we try to give voice to all patients, even those that are so few that they cannot form an association but can participate as affiliated members or individuals.

Recommendations

The Board of Directors unanimously recommends that General Assembly vote against the proposal

4. Proposal to agenda for the GA 2016 from Association GENIRIS. Revision of statutes article 5.4. Article 5.4 is to be replaced by the following articles:

Article 5.4 – Scientific Committee

Article 5.4.1. Members of the SC :

The Scientific Committee shall consist of at least three persons. The number of members of SC must be balanced by country and maybe by size of country : at least 1 member by country, 2 member by big European countries.

Members of the Scientific Committee shall be distinguished experts who have a minimum of 5 years’ experience of Aniridia, either as a practitioner or a researcher within the field of Aniridia. Primarily ophthalmologists and geneticists are eligible to become members of the Scientific Committee.

Comments

- Removing the upper limit would result in an indefinite number of persons elected, which would create less effectiveness, smoothness and rapidity in the procedures;
- There is a contradiction between the idea of balancing the members by country and the objective of having distinguished experts, and this could lead to contradictory outcomes. Let’s examine some possible situations: what happens if we do not have distinguished experts in one country? shall we have “non experts” just in order to represent the country? or what if we have two or more experts in another country, no matter if this is a “big” or a “small” country? in this case, shall we let them out? And what if we have experts willing

- to contribute but belonging to a non European country? shall we let them out, too? Scientific committees' members should be chosen only upon their expertise and commitment, not by their nationality;
- The definition of “big countries” is not clear, as we already noticed here above. Without having defined what a “big” country is, this proposal is simply inapplicable.

However, the Board of Directors recognizes that this proposal expresses a need for enlargement of the Scientific Committee. Therefore the Board of Directors will present to the General assembly a different proposal to address this need.

Recommendations

The Board of Directors unanimously recommends that General Assembly vote against the proposal.

The president of AE board and two other members of AE board designated by the GA participate by right in meetings. The secretariat of the SC is provided by a member of the board of AE.

Comments

- Considering that all Board members are volunteers and involved in many tasks, this formulation is too binding and involves too many persons from the Board;
- This formulation is not clear either, because it is unclear if the person who provides the secretariat is one of the previous three or a fourth person;
- The designation by GA means that we can elect these persons only every second year, but emerging needs during the period might require more flexibility.

However, the Board of Directors recognizes that a closer contact between the Board and the Scientific Committee is needed, and will address the issue in a different proposal of its own to be presented at the General Assembly.

Recommendations

The Board of Directors unanimously recommends that General Assembly vote against the proposal.

Article 5.4.2. Election of SC :

The Scientific Committee is elected by the General Assembly upon recommendation by the Board of Directors and the research and development Committee.

Comments

- The Board of Directors will present to the General assembly a different proposal of its own on this point.
- For what is related to the Research & Development Committee, see below at point 5.8.

Recommendations

The Board of Directors unanimously recommends that General Assembly vote against the proposal.

The Scientific Committee is elected for a period of 3 or 4 years. One of the members of the Scientific Committee is to be elected Chairman of the Committee. A second member of the Scientific Committee is to be elected Vice Chairman of the Committee.

Comments

Even though the needs expressed here for a longer commitment and a stronger structure of the Scientific Committee are reasonable, the formulation creates some problems:

- 3 or 4 years is a period that overlaps the duration of AE organs, which can produce some jamming in the procedures of election of the Scientific Committee;
- It is not clear who elects the Chairman and Vice Chairman.

These difficulties could be solved with a different formulation.

The Board of Directors will present to the General assembly a different proposal of its own on this point.

Recommendations

The Board of Directors unanimously recommends that General Assembly vote against the proposal.

Article 5.4.3. The objectives of the Scientific Committee are:

- to provide advice and recommendation to the Board of Directors on the direction of research that should be followed and therefore which research projects could be funded by Aniridia Europe or recommended for funding to funding agencies by Aniridia Europe,
- to foster communication between research groups and medical professionals across Europe and the rest of the world, with the aim of ensuring maximum visibility of research work to prevent repetition and to drive things forward at the maximum possible pace,
- to be proactive by generating proposals for research and charitable funds for projects performed by the scientific groups that the Scientific

Committee members are themselves part of (care regarding conflict of interest must be exercised in this case),

- to be highly involved in the organisation of European conferences on Aniridia.

Article 5.4.4. Meeting and work of the SC :

The members of Scientific Committee shall meet at least once a year, physically or by any appropriate medium, including telephone or electronically. Meetings are convened by joint decision of the president of the board and the President of the SC. Meetings will be announced by written or mail invitation at least six weeks in advance. The agenda and any useful information regarding decisions will be attached. If necessary, an exceptional meeting of the SC may be convened by joint decision of the president of the board and the President of the SC.

The SC maintains updated reports of its meetings and its works by the secretary of the SC. It issues a report of its activities for every 2 years by the secretary of the SC before the GA. The GA validates the action of the MSC every 2 years. The board of AE has the final decision concerning all research grant proposals presented by the SC after joint discussion between the president of the SC and the president of the board.

Comments

- The Board of Directors recognizes that rules on the functioning of the Scientific Committee are necessary to ensure effectiveness of its activities and commitment of its members, but thinks that these purposes are better served by a separate document developed as an internal by-law of the Scientific Committee.
- In fact, the Statutes are usually designed to give only the general features, leaving to the internal by-laws a more flexible definition of good practices.
- Moreover, if these rules are included in the Statutes, they become immediately binding and bureaucratic, and need longer procedures to be changed.

The Board of Directors proposes to the General Assembly to give mandate to the next Board to develop, jointly with the Scientific Committee, a by-law for the Scientific Committee addressing the issues listed above, such as meetings and reports, and any other issue that will be necessary.

Recommendations

The Board of Directors unanimously recommends that General Assembly vote against the proposal.

Article 5.4.5. Revision of the rules of the SC :

Proposals for revisions to the procedures of the SC are made by the members of the SC and/ or the members of the board of AE. They are approved by the GA.

Comments

- This formulation is inapplicable: if the procedures of the Scientific Committee are in the Statutes, then the rules for changing them must be the same used to change the Statutes (see art. 6). Any other option has no legal grounds;
- This consideration reinforces the proposal of developing instead an internal by-law.

Recommendations

The Board of Directors unanimously recommends that General Assembly vote against the proposal.

5. Proposal to agenda for the GA 2016 from Association GENIRIS. Revision of statutes article 5.6. The original text "The Nominating Committee shall consist of at least three and at the most five persons" is to be replaced by the following text: "The Nominating Committee shall consist of at least three persons."

Comments

- Here again, removing the upper limit would result in an indefinite number of persons elected, which would create less effectiveness, smoothness and rapidity in the procedures.

Recommendations

The Board of Directors unanimously recommends that General Assembly vote against the proposal.

6. Proposal to agenda for the GA 2016 from Association GENIRIS. Addition to the statutes of the following article: "Article 5.8 - research and development Committee.

The purpose of the research and development Committee is to make recommendations to the General Assembly regarding the election of one or several persons as member of the SC after joint discussion with the board of AE.

Comments

- Creating such a committee does not require a change in the Statutes, it is sufficient to use art. 5.5.
- If the General Assembly wants to create a Research & Development Committee it simply has to give mandate to the next Board of Directors to do so.

Recommendations

The Board of Directors unanimously recommends that General Assembly vote against the proposal.

b) Proposal for amendments to Art. 5.4 of the Statutes of Aniridia Europe
Presented by the Board of Directors, according to the provisions of Art. 6: *Change of these Statutes*, and to be submitted to the General assembly, that will be held in Duisburg on August 26th, 2016

7. Proposal to agenda for the GA 2016 from the board of directors. Revision of statutes article 5.4. The text in article 5.4 is to be replaced by the following text:

Article 5.4 – Scientific Committee

The Scientific Committee shall consist of at least three and at most fifteen persons. Members of the Scientific Committee shall be distinguished experts either as practitioners or researchers within the field of Aniridia. Primarily ophthalmologists and geneticists are eligible to become members of the Scientific Committee.

Comments

- The need for enlargement of the Scientific Committee can be fulfilled by rising the upper limit to 15 persons; we believe that this organ would not be able to work effectively if more than 15 persons were involved;
- Instead, it is advisable to create a larger and more flexible network of professionals connected to SC members, without them being directly involved;
- Expertise shall be the first requirement for designation, but we considered that the 5 years' experience required by the previous formulation did not guarantee it, so we propose to cancel it;
- As in the previous formulation, nationality is not mentioned for the reasons explained above.

The Scientific Committee is designated by the Board of Directors. The Scientific Committee elects a Chairperson among its members. A second member of the Scientific Committee may be elected Vice-Chairperson.

During its mandate, the Board of Directors can designate new members to the Scientific Committee upon recommendation by the Chairperson.

Comments

- During the previous mandates, the need for a quicker reaction on SC issues emerged quite often. This is why we are proposing that designation of SC members is up to the Board of Directors, whose action

is in any case bound to AE principles and to the mandate received by the General Assembly;

- Specifically, there is the need that new members of SC can be designated during the two years' mandate of the Board, to address the needs connected for example with research projects and/or to participation to the European Reference Network;
- In the previous formulation, it was not clear who had the task to elect the Chair of SC; it is our opinion that the Chairperson should be elected by SC members;
- A Vice Chairperson may be a good answer to share the burden of SC activities, but we prefer to design it more as a possibility than an obligation.

The Board of Directors may designate one or two of its members to maintain the contacts with the Scientific Committee, to provide a secretariat if needed and to participate in meetings of the Scientific Committee.

Comments

- Our previous experience demonstrates that a closer contact with the Scientific Committee could be very important to foster its actions, but we consider that establishing very binding rules could provoke a rejection by the professionals. We see very positively an involvement of members of the Board in SC activities, but we prefer to design it as an opportunity instead than a constraint for the professionals;
- As explained above, we consider that the rules for the concrete activities of SC can be better addressed in a separate and more flexible document designed as an internal by-laws of SC.

The objectives of the Scientific Committee are:

- to provide advice and recommendation to the Board of Directors on the direction of research that should be followed and therefore which research projects could be funded by Aniridia Europe or recommended for funding to funding agencies by Aniridia Europe,
- to foster communication between research groups and medical professionals across Europe and the rest of the world, with the aim of ensuring maximum visibility of research work to prevent repetition and to drive things forward at the maximum possible pace,
- to be proactive by generating proposals for research and charitable funds for projects performed by the scientific groups that the Scientific Committee members are themselves part of (care regarding conflict of interest must be exercised in this case),

- to be highly involved in the organisation of European conferences on Aniridia.

On behalf of the Board of Directors of Aniridia Europe
The President
Asbjørn Akerlie

Oslo (Norway), August 9th, 2016