



ANIRIDIA EUROPE

## **Agenda**

### **General Assembly**

**August 26<sup>th</sup>, 2016, 17.00 - 18.00**

**Duisburg, Germany**

1. Opening of the meeting
2. Approval of the agenda
3. Election of the chairperson of the meeting
4. Election of the secretary of the meeting
5. Election of two persons to check the minutes and to serve as teller if needed
6. Establishment of electoral register
7. Activity Report 2014-2016
8. Financial Report 2014-2016
9. Adoption of the Report and accounts
10. Recommendations from the Auditor
11. 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."
12. 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..”

13. 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 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.”

14. 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.

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.

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.

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.

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.

#### 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.

15. 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.

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.

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.

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.

16. 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.”

17. 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.

The research and development Committee shall consist of at least three persons. . One of these persons is assigned as Chair of the research and development Committee and is responsible for summoning the rest of the Committee and leading the work of the Committee. Eligible as members of the research and development Committee are honorary members and any representative from a full member association”.

18. Decision about granted discharge for the Board of Directors
19. Decision about the membership fees for 2017-2018
20. Discussion on Activities and proposal on Budget for 2017-2018
21. Decision on the number of members of the Board of Directors
22. Election of the president of the federation
23. Election of the vice-president of the federation
24. Election of the treasurer of the federation
25. Election of the secretary of the federation
26. Election of possible other members of the board of directors
27. Election of the Scientific Committee
28. Election of a nominating committee
29. Election of an auditor
30. Election of possible other trustees
31. Miscellaneous
32. Closing of the meeting