



Seeking A Cure For
Retinitis Pigmentosa, Macular Degeneration,
Usher Syndrome and Allied Retinal Dystrophies

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Retina International General Assembly 2018 - Auckland, New Zealand

Thursday, February 8th, 2018

Location: University of Auckland Business School

Owen G Glenn Building, 12 Grafton Road, Auckland, 1010

Room: Decima Glenn Room, Level 3

Start: 09.00 a.m. end: 05.00 p.m.

APPENDIX 04-1

Topic 04.01 New membership structure

Motion: The MC moves to accept the new membership structure and to amend the constitution and business rules accordingly.

Background

The MC evaluated the membership structure and decided that there was a need to adapt it.

The membership sub-committee proposes that the constitution of Retina International be amended to include an extra category of membership i.e. A B C category membership.

Section 4.2 of the constitution shall be amended as below.

Membership

- 4.1.1 The membership of Retina International is open to societies of people with a retinal dystrophy and organizations with a specific interest in retinal dystrophies.
- 4.1.2 In the instance of more than one full member in a country, the respective boards of the individual organisations, and their scientific and medical advisory boards (SMABs), are encouraged to meet at least once a year to avoid duplication of effort.
- 4.1.3 If such meetings take place, as described in 4.1.2, a report should be sent to the Retina International president.

4.2 Membership Classification

FIVE [Four] classes of Retina International membership exist:

4.2.1 FULL MEMBERSHIP

In order to be a full member of Retina International, a society must show that:

- 4.2.1.1 it is a charity duly registered as such under its national laws (see note to 1. Definition), and has a constitution or is a sub-group of a larger organisation, such as a society for the blind, that has a constitution
- 4.2.1.2 its purposes coincide with Retina International's objectives,
- 4.2.1.3 it is a society for people with Retinal Dystrophies such as Retinitis Pigmentosa (RP), Usher Syndrome, Macular Degeneration and other allied retinal dystrophies and their families and friends with sound scientific and medical support,
- 4.2.1.4 it may be a standalone organization or a sub-group of an organization for the blind, but in the latter case must give proof of independent activities and accept all people with retinal degenerative diseases irrespective of their stage of visual impairment. Membership should also be extended to parents of minor children with retinal conditions
- 4.2.1.5 a medical and scientific advisory board or committee has been constituted and approved by the Retina International SMAB,
- 4.2.1.6 up-to-date audited accounts have been provided to the RI Management Committee.

4.3 CANDIDATE MEMBER

A candidate member is a society which has stated an intention to apply for full membership in the future or which has already applied for full membership, but either:

- 4.3.1 In the opinion of the GA is not yet in a position to meet all the criteria for full membership, or,
- 4.3.2 Is a first-time applicant for Retina International membership which apparently meets all the criteria for full membership, in which case it must serve as a candidate member for two years prior to applying for full membership.

4.4 INTERESTED ORGANIZATION

Interested organizations include retinal dystrophy societies that are in the early stages of becoming organised and established organizations that would never apply for full membership in their

own right, for example, blindness organizations that do not have separate retinal dystrophy sub-groups.

To accomplish that people with a Retinal Dystrophy can find solace, hope and a future it is necessary to broaden the influence of Retina International. Only helping, advising and binding new groups to Retina International can do this. Therefore, the first step is interest.

Interested organizations are those:

- 4.4.1 which are not yet in a position to become a candidate member or will never qualify to become a candidate member,
- 4.4.2 which need all the support to acquire enough strength or potential to reach the next phase as candidate member,
- 4.4.3 which will be on the Retina International mailing list and will be assigned a member of the MC as primary contact.

4.5 ASSOCIATED ORGANIZATION

Associated organizations include companies, scientific institutes and funding organizations that will never be in a position to fulfil the requirements of the other membership categories of Retina International. An associated organization promotes, funds or actually conducts research into retinal dystrophies and is not enlisted to Retina International through other channels.

- 4.5.1 Associated organizations will not be present at the General Assembly unless by special invitation of the MC,
- 4.5.2 Associated organizations will have no voting rights,
- 4.5.3 Associated organizations can have a seat in the SMAB where they can help influence the course of research,
- 4.5.4 Applications to become associated organizations must be approved or rejected at the next General Assembly,
- 4.5.5 Associated organizations will pay fees.

4.6 B Category membership may be extended to organisations and patient groups who are not in a position to comply with all the requirements of full membership but wish to contribute to the work and objectives of Retina International. These organisations will be invited as observers to the General Assembly but will not be entitled to vote. The membership fees of each organisation will be determined by the finance sub- committee and will be directly proportional to the rights that they are accorded.

Membership rights at present are:

1. 2 members may attend the GA
2. They have one vote at the GA
3. Propose a member/s for the MC
4. Make representations to the GA
5. Attend the CE program
6. Apply to present at the CE
7. Have 2 delegates on the SMAB international
8. Invite delegates to attend the SMAB meeting
9. Use of RI logo
10. Details on website
11. Access to Scientific information
12. Attend the RI conference

Membership cat	Rights	Payment
Full	Full	As present
Candidate	Observers at GA and CE then 4,5,10,11,12	As present
Cat: B (Does not comply with all membership requirements)	To be determined by Membership committee in conjunction with finance sub committee	To be determined by Finance committee
Cat: Associate member	Attend CE as observers then 9 to 12	To be determined by Finance committee (at present E 500)
Cat: Interested group	As above	Finance committee

