



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

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RETINA INTERNATIONAL CONSTITUTION

Table of contents

1. Definition	page 2
2. Objectives and Functions	page 2
3. Status	page 3
4. Membership	page 3
5. Structure	page 5
6. General Assembly	page 6
7. Voting	page 7
8. Presidency	page 8
9. Management committee	page 9
10. Scientific and medical advisory board (SMAB)	page 10
11. Congresses	page 11
12. Finances	page 11
13. Disciplinary measures	page 12
14. Member resignation and expulsion	page 13
15. Business rules	page 13
16. Amendments to the Retina International Constitution	page 14
17. Liability	page 14
18. Validity and acceptance	page 14

1. Definition

Retina International, formerly the International Retinitis Pigmentosa Association (IRPA), is a voluntary, charitable “umbrella association of national societies each of which is formed by people with a Retinal Dystrophy such as Retinitis Pigmentosa (RP), Usher Syndrome, Macular Degeneration (MD) and other allied retinal dystrophies, their families and friends.”

NOTE: The laws of some countries do not allow for charitable status; in such cases it must be clear that the society has charitable purposes and is not run for profit.

2. Objectives and Functions

2.1 Objectives

2.1.1 The main objective is to promote the search for treatments for Retinitis Pigmentosa (RP), Usher Syndrome, Macular Degeneration (MD) and other allied retinal dystrophies. The main emphasis should be given to the genetically related forms of retinal dystrophies.

2.1.2 Retina International, (formerly IRPA), was created by the member RP societies to help them achieve their purposes. The main method of doing so is the exchange of ideas and information, both lay and scientific, and the encouragement of co-operation among member societies.

2.2 Function

Under the terms of the objectives, the following will be the functions of Retina International:

2.2.1 To promote and stimulate research into Retinal Dystrophies such as Retinitis Pigmentosa (RP), Usher Syndrome, Macular Degeneration (MD) and other allied retinal dystrophies. This shall be achieved by keeping in touch with scientific developments around the world and doing all in its power to foster co-operation and co-ordination among scientists with a view to expediting the development of treatments for Retinitis Pigmentosa (RP), Usher Syndrome, Macular Degeneration and allied retinal dystrophies.

2.2.2 To promote on an international and inter-Foundation basis, what the National Foundations provide on a national and inter-member basis; i.e.: mutual support and encouragement in the struggle against Retinal Dystrophies such as Retinitis Pigmentosa (RP), Usher Syndrome, Macular Degeneration (MD) and other allied retinal dystrophies.

- 2.2.3 To promote public awareness and provide information on Retinal dystrophies such as Retinitis Pigmentosa (RP), Usher Syndrome, Macular Degeneration (MD) and allied retinal dystrophies through maintenance of a high degree of international contact and exchange of literature and other useful material.
- 2.2.4 To promote the establishment of societies of persons with retinal dystrophies in countries in which such societies do not already exist.
- 2.2.5 Retina International also represents the member societies collectively to supra national organizations.

3. Status

Retina International is a global organization and therefore does not belong to any country or any member organization. Retina International is an umbrella organization of societies of people with a Retinal Dystrophy. The Constitution is the legal framework through which Retina International conducts its business. Retina International is a not for profit association according to article 60 and following of the Swiss law (ZRG) and registered in the Swiss Registry of Commerce.

4. Membership

4.1 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 classes of Retina International membership will now 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 stand alone 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 AFFILIATE MEMBER

Affiliate 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 (level1 and 2) 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. Level 3 will not be invited to the GA. Affiliate members are not entitled to send delegates to the RI SMAB meeting.

5. Structure

5.1 Composition

- 5.1.1 The affairs of Retina International are carried out by a President and three governing bodies, the Retina International General Assembly (GA), the Retina International Scientific and Medical Advisory Board (SMAB) and the Management Committee (MC).
- 5.1.2 All members of committees are honorary.

5.1.3 Decisions of all the committees are made by the majority of members present, except where otherwise stated. For decisions of the General Assembly a quorum is needed and defined as more than 50% of the full members.

5.2 Sub-groups

Under the Constitution of Retina International it is possible to form sub-groups. These sub-groups must have a specific objective or a regional character and shall be approved by the GA. Sub-groups shall observe the following rules:

5.2.1 Their activities should not conflict with those of Retina International,

5.2.2 They may not duplicate the work of Retina International,

5.2.3 As long as there is no political or economical necessity they will act as informal bodies,

5.2.4 When there is a political or economical necessity a sub-group may have legal status as long as it states in its Constitution that it recognizes the Constitution of Retina International as a higher controlling authority.

6. General Assembly

6.1 Definition

6.1.1 The General Assembly (GA) is the main governing body of Retina International and is the venue where Retina International sets its policies and priorities for the future.

6.1.2 The General Assembly shall convene on a biennial basis.

6.1.3 The General Assembly consists of two representatives selected by each society in full membership. The Retina International President shall be elected from among the full member delegates.

6.1.4 Each member society in full membership has the right to nominate a Retina International vice-president. The title of vice-president has only a promotional (PR) value and has no further influence on the activities of the organization. Each member society in full membership has one vote. A full member society may give its vote in proxy.

6.1.5 Candidate members and interested organizations may send two delegates to attend and speak at the GA, but do not have voting rights.

6.1.6 The president and the MC are responsible for the organization of the GA.

6.1.7 Any documents to be used at any meeting of the GA should be sent to the member organizations of the GA at least one month prior to the meeting.

6.2 Tasks

- 6.2.1 The General Assembly (GA) is concerned with member driven aspects of Retina International. These are understood as:
 - 6.2.1.1 The admission of new member societies to the four grades of membership (Retina International Full Member, Retina International Candidate Member, Retina International Interested Organization or Retina International Associated Organization),
 - 6.2.1.2 The determination of membership fees and utilization of donations,
 - 6.2.1.3 Selection of times and places for congresses to be held,
 - 6.2.1.4 The election of the President and the members of the Management Committee. No person may be nominated for election as President or Committee member unless he/she has the prior written endorsement of his national society.

7. Voting

Major issues may require a vote by the General Assembly. The following are guidelines:

- 7.1 The voting on matters is public unless asked to be held in a different manner by a majority of those in attendance at the meeting. Voting relating to people will always be done by secret ballot,
- 7.2 In the case of a secret ballot a voting committee of three persons selected from the members of the GA in attendance will be formed. This temporary committee will check if the votes are valid and present the results to the GA,
- 7.3 Only the full members of Retina International have the right to vote about issues at stake, and each full member has one vote,
- 7.4 A full member may give his vote by proxy. The proxy must be a qualified voting member. The president of Retina International shall be informed in writing about the proxy prior to the GA,
- 7.5 A proxy may vote for a maximum of two full members,
- 7.6 The procedure for voting by mail is laid down in the Business Rules.
- 7.7 Any Member Organization which is not fully paid-up on all dues, fees, and assessments owed by it through December 31st of the preceding year shall not be entitled to vote on any matter brought before a General Assembly for voting, nor shall any Member Organization or its members be entitled to attend any General Assembly or Continuing Education Program, or receive any continuing education credits, until such previous deficit is fully rectified by such Member Organization. A Member Organization which is in financial default but which has been granted a financing plan by the Management Committee (known as an

“Accommodated Member” or “AM”) shall be allowed to attend General Assemblies, but without having any voting privileges, and shall be allowed to participate in, and receive credits from, continuing education programs. This clause shall not apply to de minimis items such as bank charges and currency exchange rate fluctuations in connection with the payment of money owed by a Member Organization to Retina International. The provision in this Section 7.7 shall be effectuated automatically and without any action on the part of the Management Committee or the General Assembly. Nothing in this Section 7.7 shall conflict with or interfere with the authority of the Management Committee to act independently under Section 13.2.1 of this Constitution. This Section 7.7 is to operate automatically, and supersedes any sanctions or procedures written in Section 13 of this Constitution to the extent that anything in that Section 13 pertains to the subject matter contained in this Section 7.7.

8. Presidency

8.1 Definition

8.1.1 Retina International is headed by a President elected by the General Assembly (paragraph 6.2.1.4.),

8.1.2 The President must be a member of one of the full member societies,

8.1.3 The President can only be nominated with written agreement of the national society of which the proposed candidate is a member,

8.1.4 The term of office of the presidency runs from one GA to the next,

8.1.5 The Retina International President may stand for re-election any number of times,

8.1.6 Retina International’s place of jurisdiction is identical with the place of its main office in Switzerland.

8.1.7 Retina International will finance all the activities of its President for Retina International.

8.2 Function

8.2.1 Represents Retina International in all internal and external matters,

8.2.2 Chairs the General Assembly,

8.2.3 Chairs the Management Committee meetings,

8.2.4 Is required to present an annual report and associated financial statements and budgets to all members of Retina International,

8.2.5 Manages the daily affairs of Retina International,

8.2.6 Together with the Management Committee is responsible to organize the General Assembly,

- 8.2.7 Is responsible to organize a voting by mail for the positions of President and members of the Management Committee if no Congress is held within the Constitutional term,
- 8.2.8 If voting by mail shall not be possible the President and the Management Committee will remain in office with all their power of authority invested in them by Constitution.
- 8.3. Vacancy
 - 8.3.1 If the office of president is vacant or if the president declares himself/herself incapacitated and unable to continue in office or if the Management Committee (MC; see below) votes with a minimum 75% majority to declare the President incapacitated and unable to continue in office, the MC shall approve by simple majority a successor president from among MC members. The successor will take office immediately after voting and serve until the next GA, at which time a new president shall be chosen by the GA as per the procedure described above. The successor is eligible to stand for election by the GA if nominated according the above procedure.

9. Management Committee

- 9.1 Definition
 - 9.1.1 In order that the business of Retina International may be carried out without the need for all members of the GA to be consulted on every issue, a Management Committee (MC) is elected from among the members of the GA,
 - 9.1.2 The MC consists of the president and a number of other accredited representatives with full voting privileges from member organisations elected to the MC by the GA. The GA will decide on the number of seats in the MC and, by simple majority, will elect the persons to serve on the MC. Initial and continuing service as a member of the MC is contingent upon that member's sponsoring organization being in continual compliance with the financial requirements pertaining to voting privileges set out in section 7.7.
 - 9.1.3 In case of doubt or conflict it is the GA that rules; the MC derives its authority from the GA and acts on its behalf,
 - 9.1.4 The term of office for the members of the MC normally runs from one Retina International Congress to another. Should no such Congress be held for more than three years, the Retina International President shall organize an election by mail within three years of the previous election,

- 9.1.5 The members of the Management Committee may allocate tasks and positions among themselves, for example, Secretary, Treasurer, etc,
- 9.1.6 Members of the Management Committee may stand for re-election an unlimited number of times,
- 9.1.7 The members of the Management Committee shall only be nominated with written agreement from their respective national societies.
- 9.1.8 The Management Committee supports the President in managing and directing the secretariat.
- 9.1.9 The MC appoints the autitors.

9.2 Function

- 9.2.1 Promote the formation of a society of people with retinal dystrophies in countries where none exists,
- 9.2.2 Represent member societies collectively to supra national bodies (such as the European Community and agencies of the United Nations) other than the scientific and medical agencies of such bodies which are the territory of the SMAB (paragraph 10),
- 9.2.3 Together with the President, work on the policy and issues determined by the GA,
- 9.2.4 Responsibility for the delegation of tasks among themselves.

10. Scientific and medical advisory board (SMAB)

10.1 Definition

- 10.1.1 This Board deals with scientific and medical matters. Its purpose is to help national research efforts to produce the best possible results through the exchange of information and co-operation. The SMAB also informs and advises other Retina International bodies as well as national Retina International member societies in medical and research matters,
- 10.1.2 Each Retina International member society in full membership can be represented in the Scientific and Medical Advisory Board by two scientists nominated by its own Scientific and Medical Advisory Board,
- 10.1.3 The nominees will submit their curriculum vitae and a letter of commitment and interest regarding the activities of their society. The existing SMAB members will review these for acceptance,
- 10.1.4 Their term of office is usually determined by the National Medical and Scientific Advisory Board of the individual societies which they represent,
- 10.1.5 SMAB members are honorary.

10.2 Function

- 10.2.1 The SMAB represents Retina International's medical and scientific interests in supra national bodies such as the agencies of the United Nations and the European Community,
- 10.2.2 The SMAB can elect scientists from countries where no Retina International full member society exists. Once elected, they may be allocated tasks and positions among themselves,
- 10.2.3 The SMAB shall work with the General Assembly in the selection of times and locations of Congresses. It is also expected to keep the GA and the MC informed of:
 - 10.2.3.1 significant developments in the scientific and medical fields;
 - 10.2.3.2 the value of new treatments;
 - 10.2.3.3 ethical issues

11. Congresses

11.1 Definition

A biennial Congress, held preferably in conjunction with the meeting of the GA, organized jointly by the MC and SMAB.

11.2 Function

- 11.2.1 Dissemination of information on scientific research related to Retinal Dystrophy such as Retinitis Pigmentosa, Usher Syndrome, Macular Degeneration and other allied retinal dystrophies.
- 11.2.2 To foster co-operation between researchers and member organizations,
- 11.2.3 To foster the sharing of information and personal experience among affected persons and their family members and friends,
- 11.2.4 To encourage collaboration between affected persons with the aim of creating national societies in countries where they do not yet exist,
- 11.2.5 To create the opportunity for the host country to promote public awareness for the whole of their national researchers and ophthalmologists.

12. Finances

12.1. Definition

- 12.1.1 The main source of income for the President's office and associated costs stems from the membership fees as allocated by the GA and potential donations,
- 12.1.2 All Retina International members are obliged to pay membership fees as allocated to them by the GA,
- 12.1.3 The secretariat is responsible for securing funding from sources other than membership fees to fulfil its function.

12.2 Administration

12.2.1 Fees levied by the General Assembly shall be used according to the decisions of the General Assembly and are to be administered according to the law prevailing for charitable organisations in Switzerland.

12.2.2 The management and audit of the secretariat's function are to be independent of the host organisation and to be included into the accounts of Retina International and audited according to the Swiss law for non for profit organisations.

12.2.3 Signatures: The MC decides about the use of signatures that are legally binding for Retina International.

13. Disciplinary Measures

13.1 Definition

The Management Committee has the right to take preliminary disciplinary measures in the following cases.

- 13.1.1 If a member organization does not act in accordance with the Constitution of Retina International,
- 13.1.2 If a member organization harms the interest and objectives of Retina International and its members,
- 13.1.3 If a member does not follow the decisions made by the General Assembly,
- 13.1.4 Non payment of part or all of the fees allocated to the member by the GA, unless application has been made to the MC for exemption of such fees due to particular extenuating circumstances,

13.2 Preliminary sanctions

The Management Committee has the authority to take the following disciplinary action:

- 13.2.1 Reduce to the next lower position in the process of attaining membership the ranking of the subject member organization. For a full member this means taking away the right to vote and for a candidate member a new period of two years before it can acquire the full membership,
 - 13.2.2 When a member organization does not inform the management of Retina International (President and MC) of the number of members and its yearly financial statement before the month of May, the Management Committee can sanction the organization by giving it a higher ranking in the system of allocated membership fees,
 - 13.2.3 Other measures that the Management Committee deems fit to work towards protecting the interest and position of Retina International.
- 13.3 Procedure
- 13.3.1 Decisions in a case of disciplinary measures by the Management Committee will be brought to the next General Assembly for discussion and the passing of a final verdict,
 - 13.3.2 Before taking disciplinary measures the Management Committee will give the organization in question a final warning and a deadline by which time the problem should be resolved,
 - 13.3.3 If a member organization does not resolve the problem the Management Committee will inform the member organization of the (preliminary) sanction taken by the Management Committee,
 - 13.3.4 The organization has the right to speak on its behalf during the General Assembly,
 - 13.3.5 During the discussion and the final decision the representatives of the organization shall leave the meeting,
 - 13.3.6 The member representative(s) shall be informed directly after the decision taken by the General Assembly.

14. Member resignation and expulsion

- 14.1 Resignation
 - 14.1.1 A member society may resign from Retina International at any time by written notice to the President. The allocated fee however must be paid for the running year.
- 14.2 Expulsion

- 14.2.1 The GA may expel a member society if in its opinion, the conduct of that member society is prejudicial to the interests or objectives of Retina International. In case of expulsion the fee for the running year must be paid. Any fees collected up to the date of expulsion will be considered as full and final payment of any fees due.
- 14.2.2 No such expulsion shall be effective unless:
 - 14.2.2.1 such member society has been heard or afforded a reasonable opportunity to be heard in person, in writing, or in other reasonable form,
 - 14.2.2.2 it is confirmed by a two-third majority of the delegates present and voting at the next GA meeting at which a quorum exists.

15. Business Rules

15.1 Definition

- 15.1.1 In addition to and derived from the present Constitution, Retina International has a set of business rules. Those rules hold the agreements for the day to day activities of Retina International.

15.2 Function

- 15.2.1 Under the business rules fall the following decisions: System of allocated fees, voting procedures by mail, procedures for nominating of the Presidency, etc.

16. Amendments to the Retina International Constitution

Amendments of this Retina International Constitution may be made by the GA with a two-thirds majority provided a quorum exists.

17. Liability

The financial liability of the member societies for Retina International is limited to the amount of funds put at the disposal of the Retina International President by the GA.

18. Validity and acceptance

This Constitution supersedes the Constitution agreed on by the GA at Johannesburg on the 13th November 1992 and amendments made by the GA at Washington D.C. on August 15th, 1996 as well as amendments made by the GA in Lugano in July 1998, in Toronto (Canada) on July 13th 2000, in Nordwijk (Netherlands) on July 1st 2004, in Rio de Janeiro (Brazil) on October 18th 2006, in Stresa 2010, in hamburg in 2012, in Taipeh (Taiwan in 2014. This final version was ammended and accepted by te General Assembly 2018 in Auckland(New Zealand) on February 8th, 2018, with immediate effect.

Auckland, February 8th, 2018

Christina Fasser Claudette Medefindt
Prsident Debuty president