



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

## Retina International General Assembly 2014

Paris (France)

Thursday, June 26<sup>th</sup>, 2014

Location: Hotel Pullman Montparnasse, Paris

Start: 09.00 a.m., end: 4.30 p.m.

Room: Vlaminck Grommaire

### Attendees

<b>Present 23 Full Members Organisations</b>			
<b>Country</b>	<b>Organisation</b>	<b>Last name</b>	<b>First name</b>
Australia	Retina Australia	Banks	Graeme (Delegate)
		Boyd	Leighton (Delegate)
		Boyd	Rosemary (Observer)
Belgique	Retina Pigmentosa ASBL	Hallet	Benoit
		Tordeurs	Viviane (Delegate)
Brasil	Retina Brasil	Araujo	Maria Julia (Delegate)
		Leopoldi	Maria Antonieta (Delegate)
Canada	FFB Canada	apology	
Finland	Retina Finland	Palonen	Jari (Delegate)
		Rantanen	Pekka (Delegate)
France	Retina France	Filippi	Raymond (Delegate)
		Ginter	Patrick (Delegate)
		Moser	Eric (Observer)
Germany	Pro Retina Deutschland	Brohlburg	Daniela (Delegate)
		Georg	Markus (Delegate)
		Gizycki	Rainald (Observer)
Greece	Hellenic RP Society		proxi to Switzerland
Hong Kong	Retina Hong Kong	Kwan	Vincent (Delegate)
		Tsang	Kin Ping (Delegate)
Iceland	Retina Iceland (Blindrafelagid, Icelandic organization of the visually impaired (	Einarsson	Kristinn Halldór (Delegate)
		Hallfredsson	Sigthor (Delegate)
		Hjörvar	Helgi (Observer)
Ireland	Fighting Blindness	Daly	Avril (Delegate)
		Moran	Anna (Delegate)
Italy	Retina Italia	Andrao	Assia (Delegate)

		De Benedetti	Carla (Delegate)
Japan	JRPS	Kanai	Kumitoshi (Delegate)
		Morita	Sabura (Delegate)
Netherlands	Oogvereniging Nederland	Snellink	Rob (Observer)
		Sprenkels	Jos (Observer)
		Van Delden	Geert (Delegate)
		Van der Weil	Yvonne (Delegate)
New Zealand	Retina New Zealand Inc	Alexander	Fraser (Delegate)
Norway	RP-foreningen i Norge	Lagesen	Ole Christian (Delegate)
		Tollefsen	Morten (Delegate)
Pakistan	Pakistan Foundation Fighting Blindness	Yusuf	Rijie (Delegate)
South Africa	Retina south Africa	Medefindt	Claudette (Delegate)
Spain	FARPE	Bonet Ballesteros	Silvia (Delegate)
		Lopez Fuentes	German (Delegate)
		Romero Villalobos	Inés (Observer)
Sweden	Swenska RP-Föreningen	Ahlmark	Karl-Frederik (Delegate)
		Mirshahi	Susanne (Observer)
		Ramshage	Caisa (Delegate)
Switzerland	Retina Suisse	Buhl	Uta (Delegate)
		Hüsler	Stephan (Delegate)
Taiwan R.O.C.	Retinitis Pigmentosa Foundation Association in Taiwan	Lin	Chao-Ming (Delegate)
UK	RP Fighting Blindness	Head	David (Delegate)
		Jones	Stephen (Delegate)
USA	FFB	Lorrain	Christophe (Observer)
		Shea	Moira (Delegate)
<b><i>Candidate member</i></b>			
Chile	RP Chile	Serrano	Gustavo (Delegate without vote)
<b><i>Interested Group</i></b>			
Argentina	Stargardt APNeS	Mlendez Praga	Florencia (Observer)

## Agenda

- 1. Welcome and approval of agenda**
- 2. Approval of General Assembly 2012 minutes**
  - 2.1 Minutes (appendix 02-1)
- 3. President's report and financial report**
  - 3.1 President's and MC reports 2012-2014 (appendix 03-1)
  - 3.2 Financial reports 2012 – 2013 (appendix 03-2)

3.3 Fees to be written off (Appendix 03-3)

#### **4. Elections**

4.1 Retina International members (appendix 04-1)

4.1.1 Associate members

4.1.2 Interested groups

4.1.3 Candidate members

4.1.4 Full members

4.2 Retina International Officers (appendix 04-2)

4.2.1 Management Committee

4.2.2 Retina International president

4.3 Special recognitions

#### **5 Retina International Office**

5.1 Retina International Office (appendix 05-1)

5.2 Retina International Office: Job description (appendix 05-2)

5.2 Decision on budget to create a secretariat with a CEO

#### **6 Governance**

#### **7. Retina International work plans and budget**

7.1 Strategic objectives and work plan 2014/2016 (appendix 7-1)

7.2 Budget 2015/2016 president's office (appendix 7-2)

#### **8. Retina International conferences**

8.1 Retina International conference 2016 report from Taiwan (Appendix 8-1)

8.2 Retina International conference 2018 (appendix 8-2)

#### **9. Retina International marketing and information**

9.1 World Retina Day

9.2 Website

#### **10. Retina International regional sections**

10.1 Retina Europe (Appendix 10.1)

#### **11. Miscellaneous**

## **Minutes**

### **1. Welcome and approval of agenda**

Christina Fasser welcomed all to the general assembly of 2014. The roll call was performed and established, that the quorum was reached: 22 Full members present, one proxy (Hellenic Retina Society) given to Retina Suisse and one apology received by Foundation Fighting Blindnes Canada.

Minutes were to be taken by Claudette Medefindt, South Africa and Caisa Ramshage, Sweden.

Maria-Antoinetta, Leopoldi, Brazil and Rosemary Boyd, Australia were elected ballot counters.

Approval of agenda - passed unanimously.

### **2. Approval of General Assembly 2012 minutes**

#### **2.1 Minutes (appendix 02-1)**

The meeting thanked David Head for the minutes of the GA 2012. Stephen Jones, UK pointed out the new business rules had not been updated to include the latest changes and the information regarding the management committee was incorrect on the website. The President apologised and undertook to effect these changes.

The MC **motion** to "Accept the minutes of the GA 2012 in Hamburg (Germany) and to thank David Head for writing up these excellent minutes" is seconded by representatives from Retina Hong Kong and Retina Australia and passed unanimously.

### **3. President's report and financial report**

#### **3.1 President's and MC reports 2012-2014 (appendix 03-1)**

The **motion** to "Accept the president's and Management Committee reports 2012-2014" is seconded by representatives of Retina Australia and Retina Suisse and unanimously accepted.

#### **3.2 Financial reports 2012 – 2013 (appendix 03-2)**

The Auditors have recommended that the financial reports be approved.

The **motion** to "Accept the accounts 2012 and 2013 as recommended by the auditors 2013 and 2014" is seconded by Retina Hong Kong and Retina Brasil and was unanimously accepted.

#### **3.3 Fees to be written off (Appendix 03-3)**

**Retina India** are unable to pay and have suggested that they be downgraded to an Interested Group. They will re-apply for candidate membership once their financial status improves. MC recommends that they be downgraded and the fees be written off. The MC **motion** to "Downgrade Retina India to an Interested Group and the fees to be written off" is seconded by Retina Suisse and Svenska RP-Föreningen and unanimously approved.

**Iran RP Center** was a full member but are unable to pay their fees due to financial restrictions.

The MC **motion** to "Downgrade Iran RP Center to an Interested Group and the fees to be written off" is seconded by Retina Australia and Retina Finland and unanimously approved.

**Associação de Retinopatia de Portugal** are not able to pay the fees. MC recommends to be downgraded to interested group and the fees to be written off, They will be welcome to apply again once their financial situation has improved.

The **motion** to "Downgrade Associação de Retinopatia de Portugal to IG and the fees to be written off" is seconded by Retina New Zealand and Retina Brasil and unanimously approved.

**Fundación Argentina de Retinosis Pigmentaria, Argentina** are candidate members, they have been offered a down payment plan. It is to be structured as follows: A credit card payment is to be charged by the end of July, the money has to be in RI's account by the end of August, and the balance paid before the end of the year. If not fulfilled, it will be downgraded to interested group.

The MC **motion** to "grant FARP downpayment plan consisting in transferring the outstanding fees 2013 until end of August and paying the balance until 31.12.2014 to be accepted. If this downpayment plan is not fulfilled FARP will be downgraded to IG" Seconded by Foundation Fighting Ireland, Retina Italia and Pakistan Foundation Fighting Blindness and unanimously accepted.

**The Hellenic Retina Society** has been a member of RI for 25 years and has always paid their fees in time. It is a full member, but it currently faces an extreme financial situation and has requested that its membership fees be reduced for 2014 and 2015. A 25% reduction in fees for this period has been suggested by the MC. If it is not able to pay this lowered fee it will be relegated to an interested group. From 2016 it will have to revert to their normal fee.

The MC **motion** to " Grant the Hellenic Retina Society a reduction of 25% of the allocated membership fees for 2014 and 2015 recognising the fact, that the Hellenic Retina Society has always fulfilled its obligation and is a member in good standing. Should this downpayment plan not be fulfilled it is to be downgraded to an

Interested Group. From 2016 The Hellenic Retina society will have to revert to its normal fee." Seconded by Retina France, Retina Suisse and Retina Pigmentosa ASBL, Belgium and unanimously accepted.

#### **4. Elections**

##### 4.1 Retina International members (appendix 04-1)

###### 4.1.1 Associate members

###### 4.1.2 Interested groups

The RP Group of the blind organisation in Denmark has been classified as an Interested Group for the last 26 years since the Retina International constitution did not allow that it became full or candidate member. The constitution was amended in 2012 to allow acceptance of organisation in a similar situation. The RP Group Denmark was invited to apply for membership. The RP Group Denmark indicated via an email that they don't wish to become a member of Retina International and pay fees.

The MC **motion** to "Remove the RP Group Denmark from the Retina International mailing list and the website" is seconded by Retina Germany and Retina New Zealand and unanimously accepted.

Retina International will be happy to welcome Denmark back whenever they want to come back to the Retina International family as a candidate member.

###### 4.1.3 Candidate members

Stargardt APNES Argentina was accepted as a candidate member. The **motion** to "accept Stargardt APNES Argentina as a candidate member" is seconded by Retina New Zealand and Retina Brasil and unanimously carried.

According to the decisions taken under the topic 3.3 fees to be written off, **Retina India and Associação de Retinopatia de Portugal are relegated to Interested Group.**

###### 4.1.4 Full members

Netherlands are newly part of the Netherlands eye organisation but they still fulfil all the requirements for a full member. It was unanimously agreed that they continue to be full members.

The **motion** that "Retina Netherlands has turned into Ogvereniging Nederland is confirmed as Full member" is unanimously accepted.

according to the decisions taken under 3.3 fees to be written off, Iran RP Center is downgraded to Interested Group.

#### 4.2 Retina International Officers (appendix 04-2)

##### 4.2.1 Management Committee

The MC was elected as below with 21 votes for, and one abstention,

Claudette Medefindt, South Africa

Caisa Ramshage, Sweden

K.P. Tsang, Hong Kong

Fraser Alexander, New Zealand

Abdullah Yusuf, Pakistan

The management committee urged people to volunteer for the various sub committees.

##### 4.2.2 Retina International president

There was one candidate for President Christina Fasser.

The MC **motion** to "Elect Christina Fasser as Retina International President for the term of office 2014/2016" is seconded by Retina Australia, Foundation Fighting Blindness Ireland and Retina South Africa and is unanimously approved.

#### 4.3 Special recognitions

The management committee has suggested three Retina International special recognitions Awards:

One to Maria-Antoinetta Leopoldi who has been on the management committee since 2000, she started Retina Brazil, and has helped other Latin Americas countries to start their associations.

One to Professor Jean-Louis Duffier for his work in establishing Retina France.

One to Professor Jose Sahel for bringing retinal degeneration research onto the agenda of European researchers.

The MC **motion** to "Grant the Retina International special recognition award 2014 to Maria-Antoinetta Leopoldi (Retina Brazil), Prof. Jean-Luis Duffier and Prof. José Sahel" was unanimously passed.

## 5 Retina International Office

### 5.1 Retina International Office (appendix 05-1)

The motion regarding Retina International office was amended

from part-time CEO to 50% one full year funded by Retina International at a cost of 45'000 €. The Strategic plan would be written for 5 year instead of 3 year.

The MC **motions** a)"The MC of Retina International be granted permission to access core funding to allow for the recruitment of the executive director in the earliest time frame with a maximum amount of Euro 45'000 or CHF 54'500 covering a full time CEO funded 50% for one year and b) "To establish and agree on a five years strategy for the Retina International office" is seconded by Retina New Zealand and Retina Suisse and unanimously accepted.

5.2 Retina International Office: Job description (appendix 05-2)  
See 5.1.

5.2 Decision on budget to create a secretariat with a CEO  
See 5.1.

## **6 Governance**

Each organisation can nominate 6 persons to the MC, and it may be persons outside your own organisations.

Annual reports are to be sent to RI office. To date only six have been sent.

## **7. Retina International work plans and budget**

7.1 Strategic objectives and work plan 2014/2016 (appendix 7-1)  
The MC **motion** to "Accept the strategic and work plan 2014-2016 as submitted" is seconded by Retina New Zealand and Foundation Fighting Blindness Ireland and unanimously accepted.

7.2 Budget 2015/2016 president's office (appendix 7-2)  
The MC **motion** to "Accept this budget (2015 CHF 84'900.-- / 2016 CHF 82'600.--) as presented is seconded by Retina Australia and Ogverenigen Nederland and unanimously accepted.

## **8. Retina International conferences**

8.1 Retina International conference 2016 report from Taipei (Appendix 8-1)  
The Retina International conference 2016 will be in Taipei 8-10 July 2016, the last day is a half day conference.

8.2 Retina International conference 2018 (appendix 8-2)  
There was one application from Retina New Zealand to host the conference 2018. They have already secured the support from the University of New Zealand and the major interested parties.



Furthermore the organisation will be supported by Retina Australia. It is recommended that Retina New Zealand does its utmost to facilitate entrance of guide dogs to New Zealand.

The MC **motion** to "Grant Retina New Zealand the Retina International Conference 2018" is seconded by Retina Australia, Retina South Africa and Retina Suisse, carried with 21 yes and 1 abstention.

## **9. Retina International marketing and information**

### **9.1 World Retina Day**

The RI marketing team would investigate new Technologies to reach out to younger people.

the next World Retina Day will be about fundraising.

### **9.2 Website.**

More work needs to be done in order to keep the website up to date.

## **10. Retina International regional sections**

### **10.1 Retina Europe (Appendix 10.1)**

Rainald von Gizycki presented the progress report of the working group which was accepted.

No motion on floor.

## **11. Miscellaneous**

Two appeals have been sent to RI:

**Appeal 1** Horizon2020- Dr Rivolta from the research centre at the University of lausanne, wants to standardize the diagnosis of retinal degenerations. Needs support from Retinal Organisations how to find out what rights to diagnosis do patients have in different countries. Is there interest in using telemedicine in order to achieve a correct diagnosis in European countries? Application will be sent out to organisations during the next few weeks.

**Appeal 2** Dr Farber has applied for a bridging grant for a research project. They have approved funding which will only be available in January, but they need bridging finance in order to retain their experienced staff. The MC suggests "crowd funding" as a source of funding. The president would circulate more details.

Further Topics of interest:

There will be a youth meeting in Taipei for the younger patients.

There is an annual meeting in Ireland in November, and very good research papers are presented. There will be a meeting in Germany in May for the Young scientists.

Retina Switzerland will hold a meeting in April which is interesting for German and Italian speaking countries.

Paris, 26th June, 2014

For the minutes:  
Caisa Ramshagen and Claudette medefindt

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