



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

## **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 02-1**

#### **2. Approval of General Assembly 2016 minutes**

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

**Motion:** The MC moves to accept the minutes of the General Assembly 2016 in Taipeh (Taiwan) and to thank Avril Daly for writing up these excellent minutes.

# Minutes Retina International General Assembly 2016 - Taipei, Taiwan

Thursday, July 7<sup>th</sup>, 2016

Location: Taipei International Convention Centre (TICC)

Room: 401,4F

Start: 09.00 a.m. end: 1.00 p.m.

## Attendees

<b>Present 19 Full Members Organisations</b>			
<b>Country</b>	<b>Organisation</b>	<b>Last name</b>	<b>First name</b>
	<b>Full members</b>		
USA	FFB	Zilliox	Patricia
Ireland	Fighting Blindness	Dunne	Caitriona
Greece	Hellenic Retina Society	Varoux	Alexandra
Greece	Hellenic Retina Society	Chatzicharalampous	Efstratios
Japan	JRPS	Morita	Saburo
Japan	JRPS	Kanai	Kunitoshi
Japan	JRPS	Otake	
Pakistan	Pakistan Foundation Fighting Blindness	Yusuf	Abdullah
Germany	Pro Retina Deutschland	Brohlburg	Daniela
Germany	Pro Retina Deutschland	Georg	Markus
Australia	Retina Australia	Boyd	Leighton
Australia	Retina Australia	Boyd	Rosemary
Brazil	Retina Brasil	Carvalho Pinto Bueno	Rodrigo
Brazil	Retina Brasil	Leopoldi	Maria Antonietta
Finland	Retina Finland	Nyström	Timo
Finland	Retina Finland	Ketola	Heikki
Hong Kong	Retina Hong Kong	Kwan	Vincent
Hong Kong	Retina Hong Kong	Tsang	Kin Ping
Iceland	Retina Iceland (Blindrafelagid, Icelandic organization of the visually impaired)	Einarsson	Kristinn Halldór
Iceland	Retina Iceland (Blindrafelagid, Icelandic organization of the visually impaired)	Hjörvar	Helgi
Italy	Retina Italia	Andrao	Assia = Proxi to Switzerland
New Zealand	Retina New Zealand	Emirali	Sue
New Zealand	Retina New Zealand Inc	Alexander	Fraser
South Africa	Retina south Africa	Cape	James
South Africa	Retina south Africa	Medefindt	Claudette
Switzerland	Retina Suisse	Trudel	Susanne
Switzerland	Retina Suisse	Hüsler	Stephan

Taiwan R.O.C.	Retinitis Pigmentosa Foundation Association in Taiwan	Lin	Nick
Taiwan R.O.C.	Retinitis Pigmentosa Foundation Association in Taiwan	Shi-Huang	Lee
UK	RP Fighting Blindness	Houlihan	Tina
Norway	RP-foreningen i Norge	Smedstad	Martin Kristian
Norway	RP-foreningen i Norge	Tollefsen	Morten
Sweden	Swenska RP-Föreningen	Ahlmark	Karl-Frederik
Sweden	Swenska RP-Föreningen	Ramshage	Caisa
	<b>Candidate members</b>		
Chile	Fundalurp	Serrano Reyes	Gustavo Ignacio
Chile	Fundalurp	Rivera Pérez	Jaime Andrés

## Agenda

- 1. Welcome and approval of agenda**
- 2. Approval of General Assembly 2014 minutes**
  - 2.1 Minutes (appendix 02-1)
- 3. President's report and financial report**
  - 3.1 President's and MC reports 2014-2016 (appendix 03-1)
  - 3.2 Financial reports 2014 – 2015 (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 Secretariat**
  - 5.1 Retina International Secretariat: Report of the CEO (appendix 05-1)
  - 5.2 Retina International Secretariat: Work plan 2016-2018: Objectives, mile stones and outcomes (appendix 05-2) and related budget (appendix 05-3)

5.3 Decision on budget items relevant to the Retina International

Secretariat

**6 Governance**

6.3 Registration of Retina International and related changes of the constitution (appendix 06-3)

**7. Retina International basic function: work plans and budget**

7.1 Strategic objectives and work plan 2016/2018 (appendix 7-1)

7.2 Budget 2017/2018 president's office (appendix 7-2)

**8. Retina International conferences**

8.1 Retina International conference 2018 report from New Zealand (appendix 8-1)

8.2 Retina International conference 2020 (appendix 8-2)

**9. Retina International marketing and information**

9.1 World Retina Day

9.2 Website (appendix 09-2)

**10. Retina International regional sections**

10.1 Retina Europe (appendix 10-1)

**11. Miscellaneous**

## **Minutes**

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

#### **Introduction**

President welcomes the delegates to the GA and to Taiwan.

#### **Matters of Order**

Before proceeding with the scheduled agenda items Christina Fasser, president, delivers an update on the current situation regarding the typhoon. To ensure safety of delegates on the advice of the conference organisers, she suggests to reshuffle the agenda to ensure the GA concludes by 1pm to allow ample time to get to the hotels.

Leighton Boyd (Retina Australia), Hellenic Retina Society, Greece and Maria Antonietta (Retina Brasil) second the reshuffle of the GA Agenda.

Abdullah Yusuf (Pakistan Foundation Fighting Blindness) enters the meeting via Skype.

Rita Filippini carries out the roll call of members.

Tina Houlihan (RP Fighting Blindness, UK) Rosemary Boyd (Retina Australia) and Maria Antonietta Leopoldi (Retina Brasil) have been elected as scrutiners.

#### **Topic: Approval of the agenda 2016**

**Motion:** The MC moves to accept the agenda of the General Assembly 2016 with a change of order.

**Vote:** Accepted unanimously

#### **Topic: Thanks to Retina France for the RI 2014 Worldconference in Paris**

**Motion:** The GA 16 thanks Retina France for the great organisation of the RI conference 2014 in France

**Vote:** Accepted unanimously

### **2. Approval of General Assembly 2014 minutes**

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

No amendments to the minutes of last GA were received.

**Motion:** The MC moves to accept minutes of GA 2014 in Paris (France) and to thank Caisa Ramshagen and Claudette Medefindt for writing up these excellent minutes.

Seconded by: Retina Hong Kong and Pakistan Foundation Fighting Blindness

**Vote:** Not accepting minutes – no hands shown. No Abstentions.

**Vote:** Carried unanimously.

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

#### **3.1 President's and MC reports 2014-2016 (appendix 03-1)**

President and MC Report for 2014-2016 is presented.

Comments: None

**Motion:** The MC moves to accept the reports as presented.

Seconded by Retina Australia and Retina Iceland

**Vote:** Carried unanimously.

President thanks those that contributed including MC and Volunteers.

### **3.2 Financial reports 2014 – 2015 (appendix 03-2)**

President explains that the accounts are audited by the auditors appointed by Retina Suisse as host of president's office. Swiss law has changed and now a status report must be completed.

Unrestricted grants received for Patient Reported Outcome Meeting and to support the Website projects, these are within budget. The Audit and list of fees is sent annually with member invoices.

**Motion:** The MC moves to accept the accounts 2014 and 2015 as recommended by the auditors in 2015 and 2016 and to give deliberation to MC: Seconded by Retina Greece and Fighting Blindness Ireland.

**Vote:** Carried unanimously.

Daniela Capelli (staff), Rita Filippini (staff) and Abdullah Yusuf (Pakistan Foundation Fighting Blindness) are thanked for their hard work and diligence.

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

President notes that it is always the case that some organisations face difficult times.

Retina Pigmentosa ASPL, Belgium, is unable to raise funds, it is proposed they be downgraded to interested group and fees written off.

Fundación Argentina de Retinosis Pigmentaria is unable to pay fees, had have not responded to communications, it is proposed they be downgraded to interested group and the fees written off.

Hellenic Retina Society, Greece, have paid half of the amount set out in the payment based on a restructuring of fees.

The Foundation Fighting Blindness, Canada, will not spend money outside of country but wish to stay as interested group anyway. Retina International accepts their decision and proposes to draw their attention to the fact that they should pay outstanding fees to the end of 2015.

Open floor for discussion:

Hellenic Retina Society, Greece, explains its difficult position. Wishes for fees to be written off.

President notes that many organisations have difficulty.

**Motion:** President amends motion of MC to recommend to the GA to write off the amount for Hellenic Retina Society, Greece, and seek to recover the fees from The Foundation Fighting Blindness, Canada.

Seconded by Retina South Africa and Svenska RP-Föreningen, Sweden.

**Vote:** Carried unanimously.

#### **4. Elections – Items taken together**

##### **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**

Floor Given to Claudette Medefindt (Retina South Africa) who is responsible for membership.

##### ***Applications – Candidate Members***

*Association Retina Maroc* – only candidate for two year probation.

**Motion:** MC recommends they are accepted.

Seconded by Hellenic Retina Society, Greece, and Pakistan Foundation Fighting Blindness.

**Vote:** Carried unanimously.

*Fundación Retinitis Pigmentosa de Puerto Rico*

**Motion:** MC recommends they are accepted as Candidate member.

Seconded by Pakistan Foundation Fighting Blindness and Svenska RP-Föreningen, Sweden

**Vote:** Carried unanimously.

*Asociación Macula-Retina, Spain*

**Motion:** MC recommends they are accepted as a Candidate member

Seconded by Retina ry / Retina Finland and Pakistan Foundation Fighting Blindness

**Vote:** Carried unanimously

*Waiting for candidate membership forms from Cyprus*

**Motion:** MC moves to accept as candidate member once all docs are in place

Seconded by Hellenic Retina Society, Greece and Pro Retina Deutschland e.V., Germany

**Vote:** Carried unanimously

*Danish Association of the Blind*

**Motion:** Provided correct docs by end of year they are accepted as candidate member

Seconded by Retina Iceland and Svenska RP-Föreningen, Sweden

**Vote:** Carried unanimously

*Associate membership is Lirot Association the Israeli society of vision loss*

**Motion:** MC recommends application is approved

Seconded by Pro Retina Deutschland e.V., Germany and Retina Suisse, Switzerland

**Vote:** Unanimously carried

Record number for applications: six new members!

President states that a mapping of organisation within RD field is being undertaken as part of the work programme in order to ensure we are working together more effectively to achieve our goals. Treatments are coming to the market and if so there will be significant challenges and it is important to work together to get the treatments to all. Encourage all present to get other groups involved. The president thanks Claudette Medefindt (Retina South Africa) for all of her work in nurturing organisation and giving them support.

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

### **4.2.1 Management Committee – Taken together**

President states that a list of nominees for the MC sent with papers – the MC is purely a working group. Members listed will stand for re-election with two nominees, Michael Langsfeld from Pro Retina Deutschland e.V., Germany and Christin Halldor from Retina Iceland who is already working with the MC as a volunteer. Claudette Medefindt from Retina South Africa has informed the MC of her intention to retire after this term of officer also as has KP Tsang from Retina Hong Kong. There is a need then to ensure an appropriate geographic representation on the MC going forward. The MC moves to elect all candidates to the MC in order to have a smooth transition.

MC moves to elect all.

Discussion: KP Tsang (Retina Hong Kong) asked if Michael Langsfeld will represent Pro Retina Deutschland e.V., Germany. This is confirmed by the President.

**Motion:** The MC suggests to elect all candidates to the incoming MC 2016/18  
Seconded by Retina Australia and Retina Brasil

**Vote:** Carried unanimously.

### **4.2.2 Retina International President**

**Motion:** There is one candidate for president, Claudette Medefindt (Retina South Africa) proposes to re-elect Christina Fasser as Retina International president for the term of office 2016/2018 and with no other nominations moves to accept.

Seconded by Hellenic Retina Society, Greece, Retina New Zealand Inc., Retina Italia and Retina Finland

**Vote:** Carried unanimously

The President thanks the GA.

## **4.3 Special recognitions**

Two people Gordon and Lulie Gund.

**Motion:** Move to recognise

Seconded by Retina South Africa, Fighting Blindness, Ireland, Retina New Zealand Inc. and Pakistan Foundation Fighting Blindness

**Vote:** Carried unanimously



## **5 Retina International Secretariat**

### **5.1 Retina International Secretariat: Report of the CEO (appendix 05-1)**

President notes that point 7 on the agenda refers to the basic running cost of Retina International which must be covered by Membership. The activity of the CEOs office in Dublin is financed separately. For this term of office the budgets will remain separate. Retina International can still run as always. We have presented the work plan for Discussion.

Floor is open raising of hands: No hands

Seconded by Retina Australia and Retina Brasil and Retina ry / Retina Finland

**Vote:** Carried unanimously.

### **5.2 Retina International Secretariat: Work plan 2016-2018: Objectives, mile stones and outcomes (appendix 05-2) and related budget (appendix 05-3)**

### **5.3 Decision on budget items relevant to the Retina International Secretariat (taken together due to truncated agenda)**

Budget: the basis and membership fee 2017/2018. Basic costs for president's office.

**Motion:** MC moves to accept the budget as presented: Abdullah Yusuf (Pakistan Foundation Fighting Blindness) comments that it is in two parts: one is the budget of Presidents office and that is €73'400 \*surplus of 11'000\*. Then there is the Secretariat budget which has an income of € 155'000 with a Surplus income of € 850. That is the total budget of the Retina International. Two votes for the basic – Presidents office: Questions from the floor.

Seconded by Retina Italia and Pakistan Foundation Fighting Blindness

**Vote:** Carried unanimously.

CEO gives update on our secretariat and presents the Website

President updates Patient Reported Outcome project.

**Motion:** The MC moves to accept the Retina International Work and Strategic Plan 2016/18

Seconded by Retina New Zealand Inc.and Hellenic Retina Society, Greece

**Vote:** Carried unanimously

**Motion:** The MC moves to accept the budget 2017-2018 of the Retina International Secretariat:

Seconded by Retina Australia and Pakistan Foundation Fighting Blindness.

**Vote:** Carried unanimously.

## **6 Governance**

### **6.1 Registration of Retina International and related changes of the constitution (appendix 06-1)**

President outlines issues of registration: Upon investigation the CEO suggests that Retina International is registered in Switzerland. The charity

regulation in Ireland has changed and it will take significantly longer to register in Ireland which will have an impact on the operations of the organisation. Many large international foundations are registered in Switzerland and the process is simpler.

**Motion:** The MC moves to register Retina International in Switzerland. Seconded by Retina South Africa, Pro Retina Deutschland e.V., Germany and Pakistan Foundation Fighting Blindness

**Vote:** Carried unanimously.

The MC moves to accept the necessary changes in the Retina International constitution as outlined in paragraph 2.1.5:

Y=Yes

Foundation Fighting Blindness ,USA (Y), Fighting Blindness, Ireland (Y), Hellenic Retina Society, Greece (Y), Japanese Retinitis Pigmentosa Society (JRPS), Japan (Y), Pakistan Foundation Fighting Blindness (Y), Pro Retina Deutschland e.V., Germany (Y), Retina Australia (Y), Retina Brasil (Y), Retina ry / Retina Finland (Y), Retina Hong Kong (Y), Retina Iceland (Y), Retina Italia (Proxy to Switzerland) (Y), Retina New Zealand Inc. (Y), Retina South Africa (Y), Retina Suisse, Switzerland (Y), Retinitis Pigmentosa Foundation Association in Taiwan (Y), RP Fighting Blindness, UK (Y) Retinitis Pigmentosa Foreningen I Norge, Norway (Y), Svenska RP-Föreningen, Sweden (Y)

**Vote:** Unanimously carried.

MC have been given a budget but as we are now in a position where we are seeking to grow a secretariat immediate decisions may need to be taken.

**Motion:\***The MC wishes to have the authority to review an increased spending if Retina International has the funding and capacity to do so.\* Further projects not listed may be carried out provided that its funding is secured and approval by the MC is given.

Seconded by RP Fighting Blindness, UK and Pakistan Foundation Fighting Blindness

**Vote:** Carried unanimously

**Motion:** The MC proposed that all extra projects must include management costs as well as cost for capacity building for the staff involved.

Seconded by Hellenic Retina Society, Greece and Fighting Blindness, Ireland

**Vote:** Carried unanimously.

## **7. Retina International basic function: work plans and budget**

### **7.1 Strategic objectives and work plan 2016/2018 (appendix 7-1)**

President gives an overview of workplan for as laid out in papers.

**Motion:** The MC moves the GA to accept the strategic and work plan 2016-2018 for the basic running of Retina International.

Seconded by Retina Brasil, Retina Australia and Retina ry / Retina Finland

**Vote:** Carried unanimously

### **7.2 Budget 2017/2018 president's office (appendix 7-2)**

Budget is presented by Christina Fasser, president.

**Motion:** The MC moves to accept the budget 2017 CHF 73'400 and 2018 CHF 69'000 to cover the basic running costs of Retina International. Seconded by Retina Italia and Pakistan Foundation Fighting Blindness  
**Vote:** Carried unanimously

## **8. Retina International conferences**

### **8.1 Retina International conference 2018 report from Retina New Zealand Inc. (appendix 8-1)**

Report given by Fraser Alexander (Retina New Zealand Inc.). New Website to be launched. Happy that sponsorship and logistics are progressing well. Advises early booking as it is a busy time of the year.

### **8.2 Retina International conference 2020 (appendix 8-2)**

Venue for 2020 Conference – Vision 2020 object to eradicate blindness caused by poverty by 2020. Long way to go but efforts are being made. The President states that there is a choice between the possibility to a new young organisation to raise awareness at home to get people interested or and advanced organisation which can provide high value of the conference. They have this a new organisation and a long standing members in alphabetic order:

ICELAND - Retina Iceland

IRELAND - Foundation Fighting Blindness

Thanks to bidders. They leave room for private discussion.

Comments: Daniella Bromberg from Pro Retina Deutschland e.V., Germany, good that we have both one year after the other as it is a once in ten year chance for Iceland. Timo from Retina ry / Retina Finland, interested in staying in Scandinavia.

Claudette Medefindt from Retina South Africa emphasises the benefits of all day sunlight to RP patients.

KP Tsang (Retina Hong Kong) in terms of improving knowledge of science and research which is the theme of the conference, Ireland is more prepared and has good experience, he asks for clarity about science from Iceland which is a point to consider. Leighton Boyd (Retina Australia) if the reason to be in Retina International is to find a cure and assistance for Retina Dystrophies we need to think as delegates what is going to give us the best information. As delegates there is the beauty of Iceland which is good but what are we are here for. Ireland is well planned in this regard. Abdullah Yusuf (Pakistan Foundation Fighting Blindness) it is positive have two countries offer to host the conference we have and office in Ireland and could it be an opportunity to visit the office in Dublin we also need to consider this. Caisa Ramshage (Svenska RP-Föreningen, Sweden) wants to point out that Nordic countries have a common meeting once every second year and the last time in Iceland was a great success. Claudette Medefindt (Retina South Africa) – one of the other prime reasons to raise awareness of countries that can raise awareness is Russian and Iceland is close to Russia?

Following a secret ballot Iceland is chosen as the destination in 2020

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

### **9.1 World Retina Day**

Fraser Alexander (Retina New Zealand Inc.) notes that World Retina Day will take place on September 24 in 2016 and September 30 in 2017.

### **9.2 Website (appendix 09-2)**

CEO presented Website under point 5 to save time.

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

### **10.1 Retina Europe (appendix 10-1)**

Noted

## **11. Miscellaneous**

Due to nether approaching typhoon the GA has been truncated. The storm is due to be at its harshest tomorrow July 8 and so the continuous education programme will commence at 2pm and run until 5.45pm. Delegates going to the Speakers Dinner will be collected by a bus and brought to the Restaurant. President closes meeting.

Taipei, 7th July, 2016

For the minutes:



Avril Daly

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