



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

T

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.

Minutes of meeting

| Present 19 Full Members Organisations | | | |
|----------------------------------------------|----------------------------------------------------------------------------------|------------------|-------------------|
| Country | Organisation | Last name | First name |
| | Full members | | |
| USA | FFB | Chester | Yvonne |
| Ireland | Fighting Blindness | Brady | Laura |
| Japan | JRPS | Morita | Saburo |
| Japan | JRPS | Kanai | Kunitoshi |
| Pakistan | Pakistan Foundation Fighting Blindness | Yusuf | Abdullah |
| Germany | Pro Retina Deutschland | Yonchev | Dimitar |
| Australia | Retina Australia | Boyd | Leighton |
| Australia | Retina Australia | Boyd | Rosemary |
| Brazil | Retina Brasil | Martins Herance | Salete |
| Brazil | Retina Brasil | Araujo | Maria Julia |
| Finland | Retina Finland | Nyström | Timo |
| Finland | Retina Finland | Rantanen | Pekka |
| France | Retina France - Proxi to Fighting Blindness Ireland | | |
| Hong Kong | Retina Hong Kong | Kwan | Vincent |
| Iceland | Retina Iceland (Blindrafelagid, Icelandic organization of the visually impaired) | Einarsson | Kristinn Halldór |
| Iceland | Retina Iceland (Blindrafelagid, Icelandic organization of the visually impaired) | Hallfredsson | Sigthor |
| Italy | Retina Italia - Proxi to Switzerland | | |

Minutes of GA February 8th 2018 - Auckland

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|---------------|-------------------------------------------------------|---------------|-----------------|
| New Zealand | Retina New Zealand | Emirali | Sue |
| New Zealand | Retina New Zealand Inc | Smith | Mike |
| 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 |
| UK | RP Fighting Blindness | Houlihan | Tina |
| Norway | RP-foreningen i Norge | Smedstad | Martin Kristian |
| Sweden | Swenska RP-Föreningen | Ahlmark | Karl-Frederik |
| Sweden | Swenska RP-Föreningen | Ramshage | Caisa |
| | | | |
| | Candidate members | | |
| Chile | Fundalurp | Serrano Reyes | Gustavo Ignacio |
| Chile | Fundalurp | Rivera Pérez | Jaime Andrés |
| Chile | Fundalurp | Morena | Andrea |
| | Interested Groups | | |
| Argentina | Retinosis Pigmentosa | Albarracin | Francisco |

1. Welcome and approval of agenda

Christina Fasser welcomes delegates to New Zealand.

Rita Filippini takes roll call.

Sue Emirali welcomes all delegates to New Zealand.

Christina Fasser thanks Retina New Zealand for work on congress and acknowledges the work undertaken by Retinitis Pigmentosa Foundation Taiwan in successfully hosting the Retina International World Congress 2016 in Taipei.

Style of voting: It is proposed by the Management Committee there be a show of hands to vote no, to abstain and so to arrive at yes votes by deduction:

Seconded by Retina Australia, Retina Suisse, Swenska RP-Föreningen and Retina South Africa - unanimously carried, no abstentions, no objections

The MC moves to approve of agenda of the General Assembly 2018 as issued:

Seconded Retina Australia, Foundation Fighting Blindness USA, Retina Finland –

Unanimously carried

2. Approval of General Assembly 2016 minutes

2.1 Minutes (appendix 02-1)

Minutes of previous 2016 General Assembly in Taipei (Taiwan).

Avril Daly is thanked for writing up the minutes – move to approve:
Seconded Retina New Zealand, Svenska RP-Föreningen and Pakistan Foundation Fighting Blindness – unanimously carried

The President moves to special recognition award.

Jean Bennett is to be acknowledged for her outstanding work and the award will be printed at the Retina International Congress 2018:
Seconded by Retina South Africa, RP-foreningen I Norge, Pro Retina Deutschland e.V. – unanimously carried

3. President's report and financial reporting

3.1 President's, MC and CEO reports July 2016 – January 2018 (appendix 03-1) (Taken together)

President thanks CEO and MC for their dedication in the period since Taiwan.

Thanks to Claudette Medefindt for travelling to New Zealand to support the president following recent health issues.

Christina Fasser opens floor for remarks on CEO and President report.

MC moves to accept the president's and CEO report 2016-2017:

Seconded by Pro Retina Deutschland e.V., RP-foreningen I Norge and Retina Australia - unanimously carried

3.2 Financial reports 2016 – 2017 (appendix 03-2)

Christina Fasser explains due to the short time period that the fully audited accounts could not be prepared but have been reviewed.
Abdullah Yusuf gives an overview of the accounts.

Comments on accounts: Foundation Fighting Blindness USA – Yvonne Chester – asks for clarity on breakdown of running costs for administration between membership and corporate. Explained by Christina Fasser.

MC moves to accept the 2016 accounts as recommended by auditors

in 2017 and presented to you in the issued document:

Seconded by RP Fighting Blindness UK, Retina Iceland, Pakistan Foundation Fighting Blindness - unanimously carried.

MC moves to accept the accounts 2017 provided that the auditors accept them end of February 2018:

Seconded by Foundation Fighting Blindness Pakistan, Retina South Africa, Retina New Zealand - unanimously carried.

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

Christina Fasser discusses issues of membership etc. Request from Retina Hong Kong to waive 2017 fees and to be downgraded.

MC recommends to waive fees in 2017 and they remain a full member as they have already submitted a plan to pay full fees in 2018 and beyond:

Seconded by Pakistan Foundation Fighting Blindness, Retina South Africa, Retina New Zealand, Retina Australia, Foundation Fighting Blindness USA - unanimously carried

MC moves to write off the fees of Hellenic Retina Society Greece, wave the fees so they become an Interested Group – to the floor:

No Comment:

Seconded by Retina South Africa and Retina Finland – unanimously carried.

Morocco RP Association promised to pay fees and have asked to be a Candidate Member. No response despite contact made by Retina International.

The MC concludes they are unwilling or unable to pay and moves to write off the fees and relegate to interested Group.

Seconded by RP-foreningen I Norge, Retina New Zealand - unanimously carried.

Christina Fasser commends Fundacion Retinitis Pigmentosa de Puerto Rico for paying fees despite the recent devastating hurricane and difficult circumstances – Special recognition should be given – General Assembly to send greetings and encouragement.

4 Governance

4.1 New membership structure - proposal for constitutional amendment (Appendix 04-01)

Christina Fasser states the need to review the entire constitution to ensure that all amends now fit well and that they support the future direction of the organisation.

Christina Fasser gives floor to Claudette Medefindt: this year we had a number of applications from organisations we would benefit by having as members but we cannot accommodate due to current membership criteria.

Claudette Medefindt: fixing membership can be complex and it is imperative that we do not undermine the benefit of Full Membership. This must be protected. Presently there are four membership groups, the MC believes there is a growing need to add a 5th. Retina International wishes to be as inclusive as possible.

Candidate Members will not be changed. Before becoming a Full Member or Candidate Member for two years etc. This gives new and emerging groups a chance to comply.

A new membership criteria of Affiliate member is proposed:

4.2. new in the Constitution

Five classes of Retina International membership will now exist:

4.6. in the Constitution:

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 (level 1 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.

Question from USA on finance committee decisions on fees – minimum

50% of the lowest for a small organisation – for larger more established organisation who have more funding fees will be commensurate.

Claudette Medefindt reads out what benefits of new membership level one and two:

Question: RP Fighting Blindness, UK, Tina Houlihan – Is it possible to have more than one full member from one country?

Claudette Medefindt - yes provided they pay fees. This will be discussed with the national organisations but there is no veto.

Claudette Medefindt: continues with constitution 4.4 change to Affiliate Membership and 4.5 become Associate Membership.

MC moves to ask the General Assembly to accept the new membership structure including Affiliate Members as proposed:

Seconded by RP Fighting Blindness UK, Svenska RP-Föreningen - unanimously carried.

Claudette Medefindt opens to floor for questions:

Question from Germany: does this mean that you do not have Interested Groups? Christina Fasser explains that Affiliate Groups would be more established groups who are in a position to pay membership and contribute to work but do not comply with criteria for full membership. We will still have Interested Groups.

As such an amendment to the constitution needs a two third majority – the roll call method of voting is used:

Foundation Fighting Blindness USA yes, Foundation Fighting Blindness Ireland yes, JRPS yes, Pakistan Foundation Fighting Blindness yes, Pro Retina Deutschland yes, Retina Australia yes, Retina Brazil yes, Retina Finland yes, Retina France proxy Foundation Fighting Blindness Ireland yes, Retina Hong Kong yes, Retina Iceland yes, Retina Italia proxy Retina Suisse yes, Retina New Zealand yes, Retina South Africa yes, Retina Suisse yes, Retinitis Pigmentosa Foundation Association Taiwan yes, RP Fighting Blindness UK yes, RP-foreningen I Norge yes, Svenska RP-Föreningen yes - unanimously carried.

5. Elections

5.1 Retina International members (appendix 05-1)

Claudette Medefindt takes floor:

MC moves that The Foundation Fighting Blindness, Canada be accepted as Full Member.

Seconded by Pro Retina Deutschland e.V, Foundation, Fighting Blindness (USA) and RP Fighting Blindness (UK) - unanimously carried.

Returning member Retina Center Iran: on scrutiny more service orientated that a patient organisation does not fulfil criteria.

MC moves that Retina Center Iran be an Associate Member and suitable fee applied:

Seconded by Svenska RP-Föreningen, Pro Retina Deutschland e.V. – unanimously carried.

Retinosis Pigmentosa Foundation Argentina applied for Candidate Member: papers only just submitted.

MC moves provided requirements are met and fee is paid by July 2018 they be accepted as Candidate Member:

Seconded by RP Fighting Blindness (UK), Retina New Zealand – unanimously carried

Retina Tunisia indicated they would like to apply for Candidate Membership but no documents have been supplied.

5.1.1 Associate members

5.1.2 Interested groups

5.1.3 Candidate members

5.1.4 Full members

5.2 Retina International Officers (appendix 05-2)

MC is a working committee – seven standing again: Abdullah Yusuf, Claudette Medefindt, Caisa Ramshage, Fraser Alexander, Kristinn Halldor Einarsson, K.P. Tsang, Michael Längsfeld all stand – documents all provided and all nominated by home organisations

MC moves for block election of all candidates to the incoming MC 2018/2020.

Usually a secret ballot but as there are no new candidates in this case global election:

Seconded by Retina Australia, Retina Finland, Retina Suisse and Retina Iceland - unanimously carried.

Christina Fasser declares MC re-elected.

5.2.1 Management Committee

5.2.2 Retina International president election

Christina Fasser is only candidate and so the chair moves to the deputy president Claudette Medefindt – Constitution allows for a secret ballot to elect the president.

MC moves to elect Christina Fasser as Retina International President for the term of office 2018 – 2020 for global vote:

Seconded by Retina Italia proxy to Retina Suisse, Svenska RP-föreningen – unanimously carried.

Christina Fasser elected president of Retina International

5.3 Special recognitions

See above

6 Retina International Secretariat and president's office

6.1 Retina International Secretariat: Report of the CEO (appendix 06-1)

6.2 Retina International Secretariat and president's office: Work plan 2018-2020: Objectives, milestones and outcomes (appendix 06-2)

Overview on 6.1 and 6.2 provided by CEO.

MC moves to accept the CEO Report:

Seconded by Retina New Zealand, Retina Australia and Fighting Blindness (Ireland) – unanimously carried.

Claudette Medefindt asks about use of social media – what is the reason it is not widely used in the RI community?

Leighton Boyd from Retina Australia says they are reviewing their web/social media and will contribute in the future to the international site. Stephan Hüsler from Switzerland finds it difficult to use.

Kristinn Halldor Einarsson uses it and needs to be improved to encourage more traffic and activities. Sue Emirali recognises the issue and Retina New Zealand has developed a position on Facebook linked to twitter and the youth Facebook page.

Avril Daly undertakes to develop a survey to establish how to improve access and what is useful to you.

6.3 Budget 2019 - 2020 Retina International office and president's office (Appendix 06.3)

Christina Fasser introduces the budget.

MC moves that the GA 2018 accepts the budget 2019 and 2020 provided that the funding is assured. Please note that the budget is in CHF!

Seconded by Retina South Africa, Pro Retina Deutschland e.V. (Germany), Retina New Zealand and Fighting Blindness (Ireland) - unanimously carried.

7. Retina International conferences

7.1 Retina International conference 2020 report from Retina Iceland (Appendix 7-1)

Secret ballot: Rita Filippini distributing.

Yusuf Abdullah says that Fighting Blindness (Ireland) was trumped by Retina Iceland in 2020 while Pakistan Foundation Fighting Blindness is happy to host the event in 2022, they believe that Fighting Blindness (Ireland) should go ahead and they will reapply in 2024.

It is recognised that Pakistan Foundation Fighting Blindness is accepting to withdraw their application 2022 and will reapply to host the event in 2024.

Laura Brady – presents Irish bid. The proposed dates are – 4th - 8th September or 5th - 9th of October

Retina Finland has a question on weather conditions in Ireland in the Autumn. Laura Brady suggests that is generally mild but all weather in Ireland is unpredictable.

MC moves to grant the Retina International Conference 2022 to host Fighting Blindness (Ireland):

Seconded by Retina Italia, Retina New Zealand Inc., Retina Iceland and Retina Hong Kong - unanimously carried.

7.2 Retina International conference 2022 (appendix 7-2)

Update from Kristinn Halldor Einarsson on Retina Iceland congress.

Ophthalmic congress – proposes that the science meeting takes place on Thursday and Friday. The website RIWC2020 is already live.

Organising committee and Scientific committee are also established.

Open for questions: Retina Australia – Rosemary asks about distance between hotel and venue – Answer: 10 minutes

Pro Retina Deutschland e.V. (Germany) asks about youth event: yes, they have already appointed a staff member to organisation and block booked a youth hostel.

8. Retina International marketing and information

8.1 World Retina Day

Avril Daly presents intention to apply for global day through the WHO. Also, to issue materials in plenty of time to be applied locally.

Tina Houlihan, RP Foundation Fighting Blindness (UK) asks if a schedule can be prepared – Avril Daly agrees to prepare one at secretariat.

8.2 Website (appendix 08-2)

Avril Daly and Fraser Alexander present media strategy. General comments on global interactivity.

8.3 Marketing strategy (appendix 08-3)

MC moves to accept the marketing and communication strategy report:

Seconded by RP Foundation Fighting Blindness (UK), Foundation Fighting Blindness (USA) and Retinitis Pigmentosa Foreningen y Norge (Norway) - unanimously carried.

9. Retina International regional sections

9.1 Retina Europe

Agreement to promote the Retina Europe meetings more widely.

9.2 Retina Ibero – Latinoamericano

Christina Fasser: gives overview of FUNDALURP (Cile) Conference and the Memorandum of Understanding how to cooperate in their languages.

South American group has the floor: presents on the various

organisations who are working together in South America.

10. Miscellaneous

Finish organisation Retina Finland has developed research on the experience of patients with IRDs from diagnosis through their journey with the disease.

Christina Fasser mentions patient pathways in ERN for Rare Eye Disease.

Stephan Hüsler, CEO from Retina Suisse, stated that the Swiss Central union for the blind made a presentation on services – interviewed 1300 over 70 in 5-10 minutes regarding their own. one in 10 said they were Vision Impaired. 33 said they have also a hearing problem. Only two said that they are aware of services for the vision impaired.

Sue Emirali from Retina New Zealand – informed the group that they are planning to hold a pan disability meeting of youth groups currently doing really good youth connections very well. Inviting the youth groups of ministries of health and social services – adults cannot make judgement on what they should be doing.

Gustavo from Chile – new project as they do not have a guide dog school they are looking for experience in establishing this. It is suggested the speak to KP Tsang in Hong Kong who has been involved in establishing a guide dog facility recently.

Christina Fasser thanks delegates for their preparation for this meeting and their support. She closes the meeting at 2.17h

For the minutes

Avril Daly

Dublin, April 16th, 2018