



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

**Minutes of the Retina International
General Assembly (GA)
12 July 2012
Grand Elysee Hotel, Hamburg, Germany.**

Present 21 Full Member Organisations

Organisation	Country	Last name	First name
Retina Australia	Australia	Banks	Graeme (Delegate)
Retina Australia	Australia	Boyd	Leighton (Delegate)
Retina Australia	Australia	Banks	Lynette (Observer)
Retina Australia	Australia	Boyd	Rosemary (Observer)
Retina Brasil	Brazil	Da Silva Araujo	Maria Julia (Delegate)
Retina Brasil	Brazil	Leopoldi	Maria Antonieta (Delegate)
The Foundation Fighting Blindness - Canada	Canada	Bellman	Joyce Sandra (Delegate)
The Foundation Fighting Blindness - Canada	Canada	Rosenstein	Lorna (Delegate)
Retina Finland	Finland	Lindroos	Maija (Delegate)
Retina Finland	Finland	Pölkkyne	Esko (Delegate)
Retina France*	France	Frayssinet	Jean-Jacques (Delegate)
Pro Retina Deutschland e.V.	Germany	Brohlburg	Daniela (Delegate)
Pro Retina Deutschland e.V.	Germany	Georg	Markus (Delegate)
Pro Retina Deutschland e.V.	Germany	Gehrig	Claus (Observer)
Hellenik Retina Society	Greece	Chatzicharalampous	Stratis (Delegate)
Retina Hong Kong*	Hong Kong	Kwan	Vincent (Delegate)
Retina Hong Kong*	Hong Kong	Tsang	Kin Ping (Delegate)
Fighting Blindness	Ireland	Daily	Avril (Delegate)
Fighting Blindness	Ireland	Moran	Anna (Delegate)
RETINA ITALIA onlus	Italy	Andrao	Assia (Delegate)
Japanese Retinitis Pigmentosa Society	Japan	Doi	Kentaro (Delegate)
Japanese Retinitis Pigmentosa Society	Japan	Doi	Wakana (interpreter)
Japanese Retinitis Pigmentosa Society	Japan	Kanai	Kunitoshi (Delegate)
Retina Nederland	Netherlands	Van der Wiel	Yvonne (Delegate)
Retina Nederland	Netherlands	Van Eyk	Wilbert (Delegate)
Retina Nederland	Netherlands	Van der Wiel	Jacqueline (Observer)
Retina Nederland	Netherlands	Webr	Frank (Observer)
Retina New Zealand Inc.	New Zealand	Alexander	Fraser (Delegate)
Retinitis Pigmentosa Foreningen i Norge	Norway	Lagesen	Ole Christian (Delegate)
Retinitis Pigmentosa	Norway	Smedstad	Martin Kristian

Foreningen i Norge			(Delegate)
Pakistan Foundation	Pakistan	Yusuf	Rijie (Delegate)
Fighting Blindness			
Pakistan Foundation	Pakistan	Yusuf	M. Abdullah (Delegate)
Fighting Blindness			
Retina South Africa	South Africa	Medefindt	Claudette (Delegate)
Retina South Africa	South Africa	Oborn	Allison (Delegate)
FARPE	Spain	Bonet Ballesteros	Silvia (Delegate)
FARPE	Spain	Lopez Fuentes	German (Delegate)
FARPE	Spain	Romero Villalobos	Ines (Delegate)
Svenska RP-Föreningen	Sweden	Ramshagen	Cajsa (Delegate)
Retina Suisse	Switzerland	Buhl	Uta (Delegate)
Retina Suisse	Switzerland	Hüsler	Stephan (Delegate)
RP Fighting Blindness	UK	Head	David (Delegate)
RP Fighting Blindness	UK	Jones	Stephen (Delegate)
The Foundation Fighting Blindness Inc.	USA	Kahn	Alan (Delegate)

*arrived later in the meeting

***Present 3 Candidate Members with voting right after their election to Full Member
(top 4.1)***

Organisation	Country	Last name	First name
Retina Pigmentosa ASBL	Belgium	Hallet-Tordeurs	Viviane (Delegate)
Retina Pigmentosa ASBL	Belgium	Presti Filippo	Nunzia (Delegate)
Blindrafelagið, Retina Iceland	Iceland	Einarsson	Kristinn Halldór (Delegate)
Blindrafelagið, Retina Iceland	Iceland	Hallfredsson	Sighór (Delegate)
Retinitis Pigmentosa Foundation Association in Taiwan*	Taiwan	Lee	Shi-Huang (Delegate)
Retinitis Pigmentosa Foundation Association in Taiwan*	Taiwan	Lin	Chao-Ming (Delegate)
Retinitis Pigmentosa Foundation Association in Taiwan	Taiwan	Chang	Nan-Chi (Observer)
Retinitis Pigmentosa Foundation Association in Taiwan	Taiwan	Chen	Sarah (Observer)

*arrived later in the meeting

Present 3 Interested Organisations

Organisation	Country	Last name	First name
Fundacion argentina de retinosis pigmentaria	Argentina	Albarracin	Martin Francisco (Delegate)
Fundacion argentina de retinosis pigmentaria	Argentina	Ramirez	Maria Vanessa (Delegate)
Fundalorp	Chile	Serrano	Rosa (Delegate)
Fundalorp	Chile	Serrano Reyes	Gustavo (Delegate)
RP committee China	China	Yang	Jia (Delegate)
RP committee China	China	Assistant	

Apologies

Full Member

Organisation	Country
Associação de Retinopatia de Portugal (ARP)	Portugal

Candidate Member

Organisation	Country
Iran RP Center	Iran
Retina Foundation Spain	Spain

1. Introduction and Welcome

The General Assembly was opened by RI President Christina Fasser (CF) at 09:10.

CF noted the presence of representatives from new countries at this GA meeting, namely Argentina, Chile, and China expected to join the meeting. CF added that China was a notable new presence in view of the fact that the Chinese RP Society represents some 400,000 RP patients and 200,000 AMD patients.

CF announced the death last year of Saima Ammar from the Pakistani RP Society, a sad loss to Retina International, and expressed the organisations condolences to her family. The meeting stood for a minute's silence.

Roll was called by Stephen Jones (SJ) and present were as recorded above.

CF advised the meeting was being recorded to facilitate the writing of minutes and that such recordings would be deleted once the minutes were agreed.

CF asked for two volunteers to act as electoral scrutineers; Rosemary Boyd and Alison **Arbor** agreed to take on this role. CF advised that for most routine votes a show of hands would be used; only difficult issues would be voted on by roll call.

2. Approval of the Minutes of the 2010 GA, Stresa

CF advised that no amendments were being proposed to the minutes produced by David Head. The meeting also offered no amendments.

A **motion** to "Accept the 2010 GA minutes with thanks to David Head for producing them" was seconded by representatives from Switzerland and Australia and passed unanimously by the delegates present with no abstentions.

3.1 The President's Report

CF presented her report for her term of office just ended and invited questions and discussion. None were forthcoming. Claudette Medefindt (CM) expressed thanks on behalf of all present to CF for her continued commitment and valuable work for RI. CF responded by expressing her thanks to the Management Committee (MC) for all their support and hard work over the period.

The MC **motion** to “Accept the President’s Report for the period 2010-2012” was seconded by representatives from Greece and Australia and passed unanimously by the delegates present with no abstentions.

3.2 The Finance Report

CF presented the figures / finance report for the period 2010 - 2011, highlighting the following points to the GA:

- That these figures reflected an earlier decision to not increase membership fees in 2010 and 2011
- That reserves stand at over 1 year operating costs which is good, however a higher reserve would be preferred and so there is no scope for a fee reduction
- Despite dipping into reserves RI was in good financial standing
- The organisation has not had the capacity to switch from cash accounting practices to accruals accounting as discussed at the previous GA. In addition the complexities of Swiss accounting law makes this a more complex and expensive process than was originally envisaged

CF invited questions and discussion on the accounts and finances of the organisation.

Alan Kahn (USA) complimented CF on the finances and the reserves situation. He asked: noting the difficulty in switching to accruals accounting, would it not be worth investigating the cost of paying an accountant / auditor to complete the process?

CF responded that this was possible of course, based on her experience of a similar exercise elsewhere the cost would be in the order of 5,000 CHF though a formal quote had not been obtained.

Alan responded that at this price it was well worth doing. Abdullah Yusaf (Pakistan) supported this, saying that at 5,000 CHF this would be a bargain.

CF responded with a request that this be brought up under the later agenda item looking at the budgets for the next two years.

The MC **motion** to “Accept the 2010 and 2011 accounts and balance sheet, and in so doing discharge the President and MC of their responsibilities for the period”, was seconded by representatives from the USA and Pakistan and passed unanimously by the delegates present by roll call.

Note: Representatives from France and Hong Kong were not present for this vote.

4.1 Elections (Members)

At this point the representation from China had arrived and CF welcomed them to the meeting. She expressed particular welcome to Jai Yang from Beijing who was greeted with applause.

Jai Yang spoke briefly to thank CF for the welcome and to express her happiness at being at the GA and congress. The Chinese patient organisation is relatively new but represents some 400,000 members. Jai Yang herself was previously a member of the Hong Kong association. She described current scientific progress as a 'candle of hope' and was delighted to be part of the RI family.

CF deferred to CM to proceed with the election of new member organisations.

CM reported that there are now 24 full members, 6 candidate members, 14 interested groups and 1 associate member.

3 new applications for full membership had been received.

RP Taiwan

CM advised that the MC were proposing that RP Taiwan be accepted as a full member. All conditions had been met.

The MC **motion** to "Accept RP Taiwan as a full member" was seconded by representatives from the USA, Sweden and Australia and passed unanimously by the delegates present with no abstentions. The new member was welcomed with warm applause.

RP Belgium (Retina Pigmentosa ASBL)

CM advised that the MC were proposing that Retina Pigmentosa ASBL be accepted as a full member. All conditions had been met.

The MC **motion** to "Accept Retina Pigmentosa ASBL as a full member" was seconded by representatives from the USA and Australia and passed unanimously by the delegates present with no abstentions. The new member was welcomed with warm applause. Viviane Hallet-Tordeurs expressed her thanks to the GA and pleasure at the vote.

Retina Iceland

CM advised that the MC were proposing that Retina Iceland be accepted as a full member. All conditions had been met.

The MC **motion** to "Accept Retina Iceland as a full member" was seconded by representatives from the USA and Finland and passed unanimously by the delegates present with no abstentions. The new member was welcomed with warm applause.

Kristinn Halldór Einarsson expressed his thanks to the GA and pleasure at becoming a full member organisation. After a 6 year process he felt Retina Iceland had now reached “the promised land!”.

2 new applications for candidate membership had been received.

FARP Argentina

CM advised that the MC were proposing that FARP Argentina be accepted as a candidate member. All conditions had been met.

The MC **motion** to “Accept FARP Argentina as a candidate member” was seconded by representatives from Germany and Brazil and passed unanimously by the delegates present with no abstentions. The new candidate member was welcomed with warm applause.

Martin Albarracin expressed thanks to the GA and pleasure at the vote, saying this had been a four year process and FARP are looking forward very much to working with Retina International.

FUNDALURP Chile

CM advised that the MC were proposing that FUNDALURP Chile be accepted as a candidate member. All conditions had been met.

The MC **motion** to “Accept FUNDALURP Chile as a candidate member” was seconded by representatives from Canada and Greece and passed unanimously by the delegates present with no abstentions. The new candidate member was welcomed with warm applause.

Gustavo Serrano-Reyes expressed thanks to the GA. FUNDALURP was proud to have been accepted after two years.

CM noted also that over recent months RI had had communications from over 20 countries and also from many individuals in countries that could not be identified through their email addresses. At this point CM handed the floor back to CF.

Also at this point the Taiwanese delegation arrived and were welcomed to the meeting. Mr Chao Ming Lin (Nick) expressed thanks for the welcome and the earlier approval of RP Taiwan as a full member of RI.

4.2 Elections (Officials)

CF advised that all members of the RI Management Committee (MC) were standing for re-election with the exception of Stephen Jones from the UK, who was standing down due to family commitments. CF expressed thanks for Stephen for everything he had done for RI whilst in office.

The four remaining committee members were joined on the ballot list by two returning ex-members:

Alexander, Fraser (NZ)
Leopoldi, Maria-Antonietta (Brazil)
Medefindt, Claudette (RSA)
Ramshage, Caiza (Sweden)
Rosenstein, Lorna (Canada)
Tsang, KP (HK)

CF advised that KP would, if elected, also have a liaison role linking the Hong Kong, mainland China, and Taiwanese groups.

After confirming that there were no objections to the use of a show of hands rather than formal ballot papers, CF proposed a **motion** to re-elect/elect the six candidates to the MC. This was seconded by numerous representatives and passed unanimously by a show of hands with no abstention.

At this point CF passed to floor to CM, who advised that CF was the only nominated candidate for the Presidency of Retina International for the upcoming period 2012-2014. After confirming there were no objections or further nominations forthcoming CM put forward a **motion** to re-elect Christina Fasser as RI President. This was seconded by numerous representatives present and passed unanimously by a show of hands with no abstentions.

CF thanked the GA for the positive vote and for the confidence placed in her again.

4.3 Special Recognition Awards

CF asked for the GA to approve three Retina International Special Recognition Awards for 2012.

Professor Andrea Gal (Hamburg)

A respected geneticist who has worked on RP since 1984, laying ground for much of the progress made to date including the RPE65 gene therapy trials. Andreas has received numerous scientific awards, this one will be from patients in recognition of his dedication and hard work and his key role in the delivery of the 2012 congress.

Dr. Thomas Wheeler-Schilling (Tubingen)

A key scientist and behind many European vision initiatives including the European Vision Institute.

Mr Stephen Jones (RP Fighting Blindness, UK)

An outgoing member of the RI Management Committee and a long standing friend of RI. In recognition of his services to RI during long time.

CF proposed a **motion** that the GA agree to these three Retina International Special Recognition Awards for 2012. This was seconded by representatives from Canada and Switzerland and unanimously carried by a show of hands with no abstentions.

5.1 RI Office: Presentation of Paper:
“Establishing a Secretariat for Retina International”

CF set the background to the presentation of this paper which had been supplied in advance of the meeting to all delegates.

- There are clinical trials underway around the world including at Phase III
- These are critical times for retinal dystrophy research
- These are critical economic times

As an international organisation, RI wants to see all patients having access to treatments as they are developed. RI will need more resources than are currently available to work towards this.

The MC took from the 2012 GA a decision in principle to establish an RI office and paid secretariat. CF expressed her thanks to Fighting Blindness Ireland for taking this on and completing the feasibility study and paper, and handed the floor to Anna Moran (AM) from FBI.

AM presented details of the paper, also pointing out that a full copy of the feasibility study for establishing a secretariat was available online from the RI website. Key points of her presentation were as follows:

- RI was established in 1978 and is now a powerful patient led organisation with influence on retinal research
- In 2012, agreement in principle was given by the GA to creating a secretariat and the MC was charged with producing a strategy for this
- The organisation needs to “professionalise”, meaning developing a secretariat with specific paid staff to grow and develop Retina International. The use of the word “professionalise” does not imply a lack of professionalism to date.
- The plan is to strengthen, build, and increase capacity. Organisational objectives will remain unchanged.
- There are four main sections to the full paper:
 - Brief history of RI and its structure
 - Survey of members opinions on this issue
 - Emerging issues faced by RI
 - Plan for implementation
- The underlying issue is that the workload and prospective workload is too great and too complex to be handled by a voluntary post
- The member survey demonstrated strong support for the initiative, though with some caveats
 - No increase in membership fees should arise as a result

- It needs to be clarified exactly what “professionalise” means
- There must be continuity / careful handover
- Implementation needs careful coordination
- Issues in our working environment include
 - Emergence of viable therapies
 - Regulatory environment
 - Issues surrounding providing access to treatments around the world
- The secretariat would need to be proactive in these areas
- This first year of the project would include fundraising for salary, and planning
- A full year’s finance would be in place before any appointment
- Budget expected to be around USD \$ 200k
- Fighting Blindness Ireland are prepared to act as host organisation
- The secretariat will NOT report to FBI, but to the President and MC of RI

5.2 Debate on the Creation of RI Secretariat

CF proposed that there would be discussion over the paper followed by a vote on the issue as formally proposed by the MC in the paper. She then invited questions.

Alan Kahn (USA) asked about contingency planning in the event of future fundraising failure, and also about the potential approaches for funding to foundations based in the USA which might already work with FFB.

CF responded that fixed term employment contract(s) would be offered to reduce the risk to RI of fundraising failure. There is no intention to resort to asking members for financial support for the costs of the secretariat. Avril Daly (Ireland) added that several trusts in the USA have supported research work in the past, accepting the proposals would allow this to be explored further.

A Yusuf (Pakistan) asked for clarification as to what FBI would actually be contributing. Avril responded that this would be the provision of space and support, and some overhead costs would be absorbed to incubate the secretariat as a function in its own right. FBI would not be responsible for managing the secretariat - that would fall to the President and MC.

Michael Griffiths (Ireland) pointed out that the analogy is of a Chief Operating Officer reporting to the Chairman of a Board.

The representative from Spain indicated that care would need to be taken if funding was secured from (for example) a pharmaceutical company, for RI not to be seen as having any particular interest in any line of research or product. CF agreed. Some debate followed over the strength of the organisation’s current guidelines on accepting funds from interested parties.

KP Tsang (Hong Kong) indicated his strong support for the initiative in order that RI was able to maintain its momentum influencing retinal research and progress towards treatments being available. He too indicated that RI should have a clear transparent policy for accepting donations. Also he noted that the word “professionalise” needs to be used in presentations with caution, as already highlighted. Finally, KP indicated that it needs to be clear that the

function of the secretariat is to support the President and Management Committee, not vice-versa.

The representative from Finland expressed her doubts that a secretariat would bring benefits, especially regarding the provision of information to patients and patient groups. Also her concern that the fundraising basis of the proposals was short term.

CF agreed the importance of both points, assuring Maia that the quality of information being supplied would be maintained, and pointing out that as far as the financial planning was concerned, there had to be a starting point.

Lorna Rosenstein (Canada) stressed the importance of avoiding further delay and that a fully empowering motion would need to be passed now, as we do not meet again for 2 years. KP agreed and stated that the development of a fundraising policy, if needed, could progress in parallel and should not be allowed to hold up the process under discussion.

Stephen Jones (UK) congratulated FBI on the paper and proposals and expressed support from the UK representatives, that existing policy for working with industry would be adequate or could be reviewed, that fixed terms contacts would be essential, but that RI should be careful about overly relying on one group of potential funders (i.e. pharma companies). He proposed a slight amendment to part 1 of the proposal in paper 5.1 which is reflected in the final proposal below.

CF confirmed that a policy for accepting donations from industry already exists for RI. Alan Kahn (USA) pointed out the potential for conflicts of interest where approaches for funding might be made to organisations already supporting or potentially supporting the individual RI members in that country, FFB being a good example.

CF acknowledged this, indicating that a collaborative approach would always be preferred, but that to some extent we would have to accept this situation as part and parcel of being an international umbrella organisation.

Ole Lagesen (Norway) expressed support for the initiative and for slight amendments as suggested by SJ to the final motions.

Avril Daly (Ireland) pointed out that laws in Ireland and probably in many other countries are very protective of patient organisations working with industry. She also agreed that fundraising would need to be in collaboration with some individual RI member organisations but would focus on potential donors known to support international or 'cross-border' activities. She cited the European Patients Forum as a good model; the EPF started with support from 1 pharma company and is now supported by 25 sponsors.

At this point CF indicated that the meeting would break for lunch to give time for delegates to discuss the issue informally before voting straight after the break.

Presentation

Prior to the break Claudette Medefindt (RSA) called for attention and pointed out that one very important acknowledgement had been omitted when awards were discussed earlier.

This congress marks the 20th anniversary of Christina Fasser taking up the presidency of Retina International. Claudette presented to Christina, on behalf of everyone present, a certificate of thanks, acknowledging her immense contribution and hard work. The citation was read as follows:

Recognition of Christina Fasser for her outstanding work in leading Retina International in the promotion of treatments and cures for Retinal Degenerative conditions.

The 17th General Assembly of Retina International, held in Hamburg on the 12th July 2012 wishes to formally recognise the 20 years of dedicated service of Christina Fasser to the work of the International RD movement. Her outstanding commitment and steadfast determination was largely instrumental in the stability and recognition of Retina International. Her support and mentoring of fledgling organisations has ensured the steady growth of Retina International. Her vast scientific knowledge and her ability to engage with the scientists at every level has led to the acceptance of Retina International as a major role player by the Scientific fraternity. Her commitment and support of the Retina International Scientific and Medical Advisory Board has ensured the prestige of this body in the International arena.

On behalf of all those throughout the world who live with a Retinal Degenerative Disease and their families, we formally express our sincere thanks to Christina Fasser for her dedication, passion, energy and personal sacrifice to our cause over the last 20 years.

The Management Committee of Retina International on behalf of the General Assembly and Staff of Retina International.

5.2 (cont) Vote on the Creation of RI Secretariat

CF asked SJ to re-affirm the exact wording of the **5 motions** in this regard which were read as follows:

1. That a secretariat be established to support to work of Retina International under the guidance of the President and Management Committee, as described in GA Appendix 5.1 of 2012

This was proposed by the MC, seconded by Canada and Greece, and approved unanimously by a show of hands, with no abstentions.

2. That the proposed secretariat is hosted in Ireland by Fighting Blindness Ireland

This was proposed by the MC, seconded by South Africa and Pakistan, and approved unanimously by a show of hands, with no abstentions.

3. That fundraising will begin in September 2012 following the General Assembly with a proposed employment start date of April 2013.

This was proposed by the MC, seconded by Australia and Brazil, and approved unanimously by a show of hands, with no abstentions.

4. That the work plan for the secretariat be agreed by the President and Management Committee

This was proposed by the MC, seconded by USA and Germany, and approved unanimously by a show of hands, with no abstentions.

5. That appropriate amendments are made to the Retina International constitution to allow for the function of the secretariat.

This was proposed by the MC, seconded by Australia and Hong Kong, and approved unanimously by a show of hands, with no abstentions.

CF expressed her thanks to the GA for the support for these changes.

SJ affirmed that the constitutional changes required are as documented in Appendix ii of the document GA 5.1 (page 20).

CF reiterated that the accounts for the secretariat would be kept entirely separate from those of FBI, there is no financial or line management responsibility, FBI are merely going to act as hosts.

CF invited discussion over the constitutional changes; there were no questions of comments forthcoming.

The **motion** to make the constitutional changes was proposed by the MC and seconded by Switzerland and USA. Being a constitutional change voting was by role call rather than by a show of hands. The vote was unanimously carried by 24** votes with no abstentions.

** USA, UK, Switzerland, New Zealand, Hong Kong, Canada, Taiwan, South Africa, Netherlands, France, Sweden, Norway, Iceland, Italy, Finland, Belgium, Brazil, Pakistan, Ireland, Australia, Japan, Spain, Germany, Greece.

CF stated that this was a milestone for Retina International and thanked Fighting Blindness Ireland for the work that had led to the decision. Michael Griffiths from FBI thanked members for their support and said he was determined to help make the secretariat a success.

Supplementary Motion

Picking up from an earlier discussion point, CF invited voting by show of hands on KP's (Hong Kong) **motion** that the Retina International Fundraising Protocol should be reviewed / rewritten by the MC, and should include a more detailed statement than currently exists, in particular in regard to the organisation's relationship with pharmaceutical companies.

This was seconded by representatives from Norway and Ireland and carried unanimously with no abstentions.

6.1 Governance – Business Rules (appendix 6.1)

At CF's request SJ presented paper 6.1 which, because it ran to some 40 pages, SJ said he was not intending to read out loud in full!

Paper GA 6.1 (2012) consolidates the business rules of the organisation, reflecting changes in the membership structure, and other updates and amendments as required. SJ pointed out that the rules have not been totally rewritten, this document is a revision based on the existing version.

SJ summarised as follows:

Section A – Basic Business Rules	Unchanged
Section B – World Conferences	Unchanged
Section C – Membership Structure	Amended to reflect changes agreed in Stresa whereby membership is organisational rather than country based
Section D – Fee System	Updated and Associate organisational membership included
Section E – Fundraising	Unchanged (at present)
Section F – Travel Grants	Unchanged
Section G – Use of logo	Unchanged
Section H – Powerpoint	Unchanged
Section I – Accessibility	Unchanged
Section J – Interpretation	Unchanged

These notwithstanding minor changes to presentation, spelling and grammar.

6.2 Governance – Votes in Respect of the Business Rules (appendix 6.2)

The motions to accept the updated Business rules were presented as Appendix GA 6.2 (2012) and voted as follows:

1. **Motion** to create Annex 1 to Business Rules Section C – Procedure for Dealing with an Additional Application from Within a Country.

No discussion points were raised. Proposed by the MC, seconded by representatives from Norway and Sweden, and carried with votes for 23, votes against 1 (Spain), abstentions 0.

2. **Motion** to amend Annex 2 of Business Rules Section D – RI Fee Policy Amendments.

Discussion points: In answer to a query from the German representative, SJ explained that caps introduced in 2006 had led to fee calculations being unworkable and unclear. Proposed Retina International, GA 2014, Paris Montparnasse - Paris
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by the MC, seconded by representatives from Australia and Greece, and carried unanimously with no abstentions.

3. **Motion** to create Annex 4 to Business Rules Section D – Fees Applicable to Associated Organisations.

Discussion points: DCH (UK) suggested that the word 'initially' should be added to facilitate future increases in fees. In response to a suggestion from the German representative that an organisation's size should be a factor in determining the membership fee, CF stated she felt it would be better to seek 'sponsorship' from larger organisations in addition to the fees payable. The representative from Greece asked how a government department or organisation would be classified; CF responded that such an organisation would be an Associate. SJ advocated simplicity as important. The motion was proposed by the MC, seconded by representatives from the USA and Switzerland, and carried unanimously with no abstentions.

4. **Motion** to Approve the Revised Business Rules and Policy Papers

No discussion points were raised. This motion was proposed by the MC, seconded by representatives from Canada and New Zealand, and carried unanimously with no abstentions.

6.3 Governance – Mission Statement (appendix 6.3)

At CF's request a proposed newly worded RI mission statement was read aloud and is reproduced here for clarity:

"Retina International's mission is to do all in its power to facilitate the earliest possible development of treatments and cures for retinal degenerative conditions such as retinitis pigmentosa, macular degeneration, Usher syndrome and allied retinal dystrophies and to ensure that all patients have access to accurate diagnosis, genotyping and registered treatments in the shortest time possible."

No discussion points were raised when invited. This **motion** was proposed by the MC, seconded by representatives from the UK and Germany, and carried unanimously with no abstentions.

6.3 Governance – Guidelines for Officers and Employees of RI in Respect of Participation in Clinical Trials (appendix 6.4)

CF introduced this paper, pointing out that if an employee of officer of RI was to take part in a clinical trial the issues would become very personal. She felt it would be unfair to ban such involvement but that RI needs to be clear about potential conflicts of interest or about undue influences. Hence these guidelines were presented for approval. CF invited discussion over the document.

The Norwegian representative commended and thanked the MC for dealing with the issue, which needs to be taken seriously. He felt the paper was well balanced.

No other discussion points were raised when invited. The **motion** to adopt the guidelines with immediate effect was proposed by the MC, seconded by representatives from the RSA and Canada, and carried unanimously with no abstentions.

7.1 Strategic Objective and Work Plan 2012/2014 (Appendix 7.1)

This paper was presented by CF. Comment and discussion was invited. No discussion points were raised.

The **motion** for the General Assembly to accept the work plan as presented was proposed by the MC, seconded by representatives from Greece and Australia, and carried unanimously with no abstentions.

7.2 Budget 2013/2014 President's Office (Appendix 7.2)

This paper was presented by CF. Comment and discussion was invited.

CF advised that the paper presented basic running costs for the office, and that work was needed to increase reserves.

CF advised that all member organisations would stay in the same band as currently, with the exception of Portugal which would be moved down one band. Taiwan would be treated in the same way as Hong Kong as it would not be fair for fees to be based on the broader Chinese economy.

The representative from the USA proposed that a motion be added to the paper to the effect that "The MC be given the authority to at its discretion to incur the expense of making the conversion to accruals accounting to avoid any further delay."

The representative from Spain asked that Spain be also moved to a lower cost band. CF responded that this request would need to be submitted to the MC. The Spanish representative concurred, but indicated a desire to highlight the impact of the economic crisis in Spain.

The representative from Pakistan asked for clarification over the impact of the earlier secretariat decision. CF responded that the budget was for basic costs as borne by membership fees and that if the venture does not succeed, RI would merely continue as-is. Thus accounting for the secretariat project would be handled separately.

CF called for more discussion prior to a vote to accept the budget. The motion to change accounting format proposed by the representative from the USA was to be included and an additional expenditure of up to CHF 5,000 to be added for this.

The **motion** to accept the proposed budget, as amended with the addition of a further CHF 5,000 of expenditure, and providing the MC the authority to, at its discretion, incur this expense in making the conversion to accruals accounting, was proposed by the MC. This

motion was seconded by representatives from New Zealand and Australia and carried unanimously with no abstentions.

8.1 Retina International Conference 2014 (Appendix 8.1)

CF invited the representatives from France to update the GA on planning for RI 2014, and translated the subsequent narrative summarising the paper already submitted as appendix 8.1. In addition the following points were made:

- RI 2014 will be in Paris on 12 and 13 July 2014. 14 July is a French holiday – Bastille Day – which is worth staying on for the celebrations.
- The layout and format will be broadly as usual'
- A satellite event sponsored by Novartis will focus on AMD
- One afternoon session will be for optometrists / opticians.
- There have been changes on the Retina France board but this will not impact on event planning.
- The event will cater for a maximum of 1,500 participants.
- Plenty of hotels to fit various budgets are available close to the event venue.

8.2 Retina International Conference 2016 (no appendix)

After a short break the Taiwanese delegation gave an exciting and interesting presentation asking for the GA to approve that RI 2016 is hosted in the city of Taipei.

The theme proposed is East Meets West and the group have the support and some investment from the Taiwanese government should the event go ahead. The event would be delivered in partnership with Retina Hong Kong.

After an excellent presentation CF proposed that the 2016 RI Congress be held in Taiwan. This **motion** was seconded by representatives from Pakistan and the Netherlands, and approved unanimously with no abstentions.

9.1 World Retina Day

This item was on the agenda at the request of the Australian representative, who felt that last year there had been too much emphasis during this event on macular degeneration and not enough on retinitis pigmentosa.

The representative from New Zealand concurred, suggesting that RI could issue multiple statements and press releases if necessary. CF agreed and said that AMD and RP – focussed communications should present no problem.

The representative from Ireland indicated that she felt World Retina Day had been 'hijacked' by AMD Week, and queried whether a different date should be chosen. However the representative from the RSA said that the event should be collaborative and she would be worried about making this change.

This discussion was concluded without a motion or vote.

9.2 Website

CF reported that the RI website (www.retina-international.org) has now been transferred to a new technical platform and updated.

CF indicated that it was essential that if the website was to remain useful it needed to be kept up to date and this is reliant on the various member organisations providing information.

All member organisations were requested / urged to keep the Retina International office updated with details of events and organisational news.

10.1 Retina Europe (appendix 10.1)

This paper was presented by the representative from Germany, who indicated it was intended to be a status report on Retina Europe (RE). RE is a subsection of RI, and its main activity is building relationships with a number of specific European organisations, i.e. doing what RI would like to be doing at a European level.

Details of these organisations and of RE activities is included in the appendix.

The representative from Germany proposed motions asking that this paper be taken into account by the MC and President of RI, and that RI accepts the principle of Retina Europe and gives it a mandate to undertake the activities outlined.

CF responded that Retina Europe is already in place and was adopted in 1998, so these proposals were not needed. She felt that creating a sub-committee of the MC to deal with Europe focused activities would be a better approach.

CF proposed alternative motions:

1. That the GA accepts the report of RE and wishes the activities to continue in cooperation with the MC.
2. That the MC study how RE can operate within RI and make representation and recommendations to the GA in 2014.

And that proposals contained in Appendix 10.2 are dropped.

Avril Daly (Ireland) appealed however for all European member organisations to get involved in various ongoing European organisations and activities.

Motion 1 above was proposed by CF, seconded by representatives from Switzerland and Spain and carried unanimously with no abstentions.

Motion 2 above was amended on a suggestion by the Canadian representative to read as follows:

2. That the MC study how **regional groups around the world** can operate within RI and make representation and recommendations to the GA in 2014.

This was proposed by CF, seconded by representatives from Australia and Spain and carried unanimously with no abstentions.

11. Miscellaneous (Any Other Business)

CF invited contributions from any delegate.

Delegates from Spain, Australia, Chile, Ireland, Finland and Belgium highlighted upcoming ophthalmology events in their respective countries and invited other delegates to attend (not detailed in these minutes as event dates will have passed before publication).

Avril Daly (Ireland) advised that Fighting Blindness Ireland will be 30 years old in 2013 and events will be planned to mark this.

Several delegates expressed thanks and appreciation to Retina International and Christina Fasser.

CF closed the GA at 17:25, commenting that the meeting had been “a good day with some good decision”.

END

Minutes recorded by
David Head
RP Fighting Blindness (UK)