



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

## **General Assembly Meeting of Retina International 2010**

**Date: Friday, June 25th, 2010**

**Location: Palazzo dei Congressi di Stresa, Piazzale Europa, 3, -  
28838 Stresa (VB) Italy**

**Time: 09.15 - 18.00**

Present: 21 Full members (Roll Call)  
Australia, Ireland, New Zealand (NZ), South Africa (SA),  
United Kingdom (UK), United States of America (USA),  
Finland, Norway, Sweden, Switzerland, France, Germany,  
Italy, Brazil, Portugal (arrived late in proceedings), Spain,  
Pakistan, Netherlands, Greece, Hong Kong, Japan

2 Observer members: Iran, Iceland

### Apologies

Canada, Lorna Rosenstein (Management Committee  
(MC), due to ill health)

### Candidate Countries

India (expected at congress, not present at GA), Taiwan  
(not present at GA), Belgium

### Chair / Secretariat

Christina Fasser (CF) (Chairperson), Daniela Capelli

### Observers

12 observers were present (but not at table) from Greece,  
Germany, Australia, Switzerland, Sweden, Finland,  
Norway and Netherlands

### **Apologies:**

Canada, France, Spain (Foundation Retina Spain)

**Proxy:**

Canada to D Waldron (Ireland)

France to C Fasser (President)

**Absent:**

Retina Hungary (No proxy given)

**Agenda:**

1. Welcome and approval of agenda
2. Approval of general assembly 2008 minutes
  - 2.1 Amendments received (appendix 01-1)
  - 2.2 Minutes (appendix 01-2)
3. President's report and financial report 2008/2009
  - 3.1 President's and MC report (appendix 02-1)
  - 3.2 Financial reports 2008 – 2009 (appendix 02-2)
  - 3.3 Unrecoverable fees (Appendix 02-3)
- 4 Membership structure (Appendix 03)
- 5 Constitutional amendments to incorporate the new membership structure (Appendices 04-1, 04-2 and 04-3)
6. Elections
  - 6.1 Retina International members (appendix 05-1)
    - 6.1.1 Associate members
    - 6.1.2 Interested groups
    - 6.1.3 Candidate members
    - 6.1.4 Full members
  - 6.2 Retina International officers (appendix 05-2)
    - 6.2.1 Management committee
    - 6.2.2 Retina International president
  - 6.3 Special recognitions
7. Retina International work plans and budget 2010/2012
  - 7.1 Strategic objectives and work plan 2010/2012 (Appendix 06)
  - 7.2 Budget 2010/2012 (appendix 07)
8. Retina International conferences
  - 8.1 Retina International conference 2012 (Appendix 08)
  - 8.2 Retina International conference 2014 (appendix 09)
9. Retina International marketing and information
  - 9.1 World Retina Day
  - 9.2 Website
10. Retina International regional sections

## 11. Miscellaneous

## **1. Welcome and Approval of Agenda**

CF introduced herself and welcomed delegates and countries to the General Assembly (GA). CF explained the resolution, motion and voting process and that the meeting would observe the 'Roberts' rules, in order that every delegate had a fair opportunity to have their say and that voting by call is processed in order to be fair to visually impaired delegates.

CF confirmed that 21 (of 23) full members present was a quorum. Also that David Head (UK) was taking minutes and that, to facilitate this, the meeting being recorded. There were no objections to this. CF clarified that only when the table microphones were used could we guarantee that a contribution would be recorded.

CF welcomed the candidate countries Taiwan, Belgium and India. She also advised interest in RI had been expressed in Argentina and Chile and welcomed the growth of the RI family.

Three of the observers were asked to oversee the later election of officers and any other necessary secret vote: Rose Boyd (Australia), Zaar Horst (Germany), Corrine Hochuli (Switzerland).

CF took the opportunity to mention two people closely linked to RI who had recently received honours: Michael Griffith (Ireland) had been awarded an honorary Doctorate from Trinity College, Dublin for his achievements and Mary Guest (UK, not present) had been awarded an MBE in the UK's Queen's honours list. Both were applauded and congratulated by the GA.

CF thanked the Finnish group for a successful 2008 conference in Helsinki and this was also applauded. She also thanked Retina Italia for organising the 2010 event and congratulated them on the excellent venue.

Delegates were asked if any business needed to be added to the agenda for the GA as published. Two items were raised and dealt with immediately:

- Claudette Mendefint (SA) asked the GA to congratulate CF on her prestigious award from the American Association for Vision Research (ARVO special recognition award). This was warmly applauded. CF said this had been accepted on behalf of all at Retina International and dedicated to all people around the world with RP.
- The Spanish delegation requested that consideration be given by organisers of the 2012 event to providing Spanish translation services at the event. CF noted this request.

There being no other items raised CF confirmed the agenda as approved.

## **2. Approval of GA 2008 minutes**

Motion: Minutes of the 2008 meeting as provided by David Waldron and with two minor amendments submitted by Norway. to be accepted Both documents had been circulated earlier as Appendix 01-1 and Appendix 01-2.

seconded by NZ and SA and carried unanimously.

## **3. President's report and financial report 2008/2009**

### **3.1 President's Report (Incorporating MC Report) circulated as Appendix 02-1.**

CF presented the President's reports for approval by the GA. She highlighted that the MC had had a tough two years, Dave Waldron has had to step down due to other commitments, Claudette has been ill and Lorna is still unwell and will be stepping down. Nevertheless CF reported being proud of achievements in the period, notably the 'Registry of Registries (shortly to be published on the website). CF invited questions and comments.

Finland: Suggested that in future the organisers of the Congress should be noted and thanked in the President's report as this would be the only official record of their involvement. CF agreed to action

this in future, and pointed out that it is also recorded in the GA minutes.

Norway: Referencing section 3.6 of the report, it is deplorable that there is no youth event at this Congress, and Germany should be encouraged to remedy this in 2012.

UK: Reiterated this same point noting that several UK members had expressed interest in attending in 2010 if a youth programme had been included.

Ireland: Congratulations to CF and MC on the achievements of the period, particularly the Registry of Registries, and does this include registries outside Europe? CF responded that four non-European registries were included and took the opportunity to thank Fighting Blindness Ireland for their support during the project.

Motion: GA was asked by CF to approve the President's report. This motion was seconded by Pakistan and Sweden and carried unanimously to applause.

### 3.2 Financial Report 2008 – 2009 circulated as Appendix 02-2

CF presented the 2008 and 2009 accounts for approval, highlighting the following:

- Capital stands at CHF 189,300 and there was an operating Deficit CHF 11,700
- Accounts are on a cash basis thus income for 2008 for projects is offset by project expenditure in the following year. EVI Genoret and EuroVisionNet are cases in kind. Project funds are also earmarked for continued expenditure from earlier recorded income, leaving organisational capital of CHF 128,000
- Underlying running costs (operational expenditure) have been contained within budget
- Organisational capital covers 2 years running costs which is healthy but leaves no room for manoeuvre
- Auditors are recommending the write-off of several outstanding fees, to be discussed shortly

CF invited questions and comments.

USA: Accounts on a cash but should contain footnotes explaining cash basis and any significant differences that would arise if an accruals basis were used.

Pakistan: (1) consideration should be given to using accruals based accounting (2) unrecoverable fees should ideally be stated in 2009 figures (3) can CF clarify regarding the EuroVisionNet finance: income for 2008 was CHF 55,000, CHF 11,000 was spent, leaving some CHF 44,000 still to be spent? CF confirmed that this money is being spent over 2009 and 2010, and that under EU processes the grant for the 3 year project was paid in advance.

Pakistan: This makes the surplus (2008) and deficit (2009) misleading. Happy that underlying expenditure is under control but of the view that accruals accounting should be used, or at the minimum more detailed notes should be included under the cash accounts.

CF noted and agreed this point, and that it reflects the growth of RI's involvement in projects. As he is a chartered accountant CF asked for Mr Yusuf's advice and support over the next accounting period to make a transition to accruals accounting in a transparent way. This Mr Yusuf agreed to do.

Motion GA was asked by CF to approve the financial report. This motion was seconded by USA and Australia and carried unanimously. CF thanked the GA for their approval and formal discharge of the MC's financial responsibilities.

### 3.3 Unrecoverable Fees

Circulated as Appendix 02-3, CF presented a proposal to write off unrecoverable fees due from Hungary, Panama and Poland. Panama and Poland were to be reclassified as Interested Groups and Hungary reclassified if payment was not made by 31<sup>st</sup> August 2010. Poland and Panama were dormant and have not reacted to communications. Hungary was still a working group and would like the additional time to pay.

In response to queries from the UK and Sweden, CF said the reclassification was the sanction outlined in the constitution and that to rejoin an organisation would have to go through the whole RI process again.

Motion: That RI write off the fees of Panama and Poland and reclassify them as Interested Groups  
Seconded: Switzerland and Pakistan  
Unanimously carried

Motion: That RI write off the fees due from Retina Hungary if they are not paid by 31<sup>st</sup> August 2010. In this event the group would also be reclassified.  
Seconded: Greece and Germany  
Unanimously carried

CF noted that this also clarifies the accounting of fees. CF took this opportunity to thank Alan Khan (USA) for his activity driving members to pay fees more promptly, and also to the GA for agreeing this action reinforcing it.

#### **4. Membership Structure**

At the opening of this topic congratulations were extended to Greece and France for 20 years of their organisations, and to South Africa for 30 years. The Pakistan delegation highlighted the fact that they had been around for 22 years!

CF called on Stephen Jones (SJ) from the UK to present proposals for changes to the membership structure, previously circulated as Appendix 03. SJ introduced himself and the paper – Towards an Organisation-Based Membership. The paper had also been discussed at the Continuing Education Day (previous day) by most of the delegates present. SJ introduced the following key points but suggested that it was not appropriate to discuss every detail in depth because the paper has been circulated and discussed already and time would not permit.

- Proposal to move to Organisation-Based Membership is NOT about encouraging multiple applications from each country. One strong national body per country is a good

model and credit is due to countries (example cited: Brazil) that have worked hard to create this. Not about fragmentation

- Rather, we are trying to accommodate difficult situations, for example China. Here we recognise that one national body is highly unlikely (“more or less unthinkable”). An application from Taiwan is in hand and we already have a member in Hong Kong. We hope that in future applications may arise from mainland China. At present our constitution does not accommodate this.
- Sometimes applications come from second organisations representing the same groups in a country
- Proposal is that we move to an Organisation-Based Membership whilst at the same time not undermining those countries where one body exists.
- Basic principles and membership criteria of RI remain unchanged.
- Membership categories will also be rationalised to full (to include sub-groups of larger blind societies), candidate, interested groups, associated groups.
- Adopting these new principles will also need the GA to approve constitutional changes.
- Voting rights will be simply one organisation = one vote.
- A capping system could be introduced in the event of a significant number of organisations joining from one country, which is seen by the MC as being highly unlikely.
- Fees would be due calculated as at present, then shared amongst the organisations from each country but the total fee would be uplifted by 25% for each additional organisation that joined.
- Several motions will arise from this proposal paper
  - To move to an Organisation Based Membership
  - To approve membership criteria
  - To approve membership categories
  - To approve the principle of a vote-capping system if needed in the future
  - To approve the shared fee structure including an uplift

CF invited comments and questions from delegates.

Ireland: Congratulations to SJ on the work and a very good plan. Very supportive of the plan but perhaps the fee uplift should be increased, proposing 50% for each additional member organisation. This was tabled as a motion.

Germany: A good proposal to which Germany is fully agreed, and again the uplift should be higher. Also, proposing that fees should be extended to include Associate groups.

Pakistan: Again, congratulations to SJ for a job well done. Understand the need to get maximum number of countries involved in RI, and making it easier for China large countries to do so is welcome. Problem however is large areas that are not represented, eg the Middle East, Africa, parts of South America, and so are we making this step a little too early? Pakistan will support the principle if it does get accepted. Supportive of the changes to categories but on fees, the link to GNI needs to be reviewed and the uplift proposed needs to be increased. In response CF advised that the fee structure and link to GNI is not up for discussion at present.

USA: Seconding Germany's suggestion that Associates pay fees, with a reduction for not-for-profit organisations. Supportive of the whole proposal but uplift should be 100%, quoting "no representation without taxation" as the principle – ie for voting rights the full fees should be paid.

Spain: (*paraphrased minute*) Spain is against the proposals as the delegation believes that each country should be represented by one vote, and that it will be more difficult to reach agreements under the system proposed. Also, the organisation (FARPE) has paid considerable amounts to RI and would be undermined by the proposals and the involvement of other groups from the same country.

Finland: The proposals should have been sent earlier to allow for discussion by the national / organisational boards. 6 months would be appropriate to allow for both translation of documents and discussions; this will be more important as RI grows. This applies to

other communications too, especially where changes to the constitution are to be discussed.

Norway: This discussion was in fact started two years ago; they confront the main issues, especially blind society subgroups, and Norway endorses this. Important too that RI moves to 'kick out politics' and not adopting the proposed changes will not do this. Member categories are much better. However there is still the danger of fragmentation under the proposed uplift structure and Associates should be fee paying.

Greece: In Greece there are plans to create more RP societies. Collaboration might be difficult and Greece is concerned about the dilution of their vote if a number of other organisations were to join RI. In response CF noted that the principle proposed is 'One member = One vote' not "One country = multiple votes".

Netherlands: Netherland spoke against the proposals, stating that they felt the proposals DID undermine the existing members, and in moving to support large low and middle income countries actually weighed against smaller, richer nations such as Holland. Overall the proposals are not good for RI. Worldwide fragmentation of countries such as USSR and Yugoslavia would give us plenty of opportunity to grow under the existing membership arrangements. The Netherlands' experience was also that the creation of a second organisation was causing problems too with the make-up of the Medical Advisory Boards as scientists were being approached by that group, potentially resulting in a reduction in the quality of both boards. In addition, the Netherlands delegation felt aggrieved that RI had not advised them of an application to join from the second organisation.

CF responded that the group was indeed informed but now the application has been withdrawn anyway.

Netherlands: Firmly against the proposals, disappointed with the MC over the whole issue and the communications. Would like now to propose that "if there is a second organisation in a country that wants to be a member (of RI) the existing member will be asked for advice and has a veto right on that second organisation to join or not to join RI".

CF noted that this would entail a constitutional amendment and suggested “*The MC is tasked with submitting to the next General Assembly that in the case that there is a second organisation in a country that wants to be a member (of RI) the existing member will be asked for advice and has a veto right on that second organisation to join or not to join RI*” in order that this could be taken at this GA. This was agreed by the Netherlands delegation and will be considered under constitutional amendments, in the meantime CF returned the meeting to the subject of the new membership structure.

Brazil: Welcomed the proposed changes, but noted that the member-vote and member-fee relationships may need clarification as the latter is still country based.

SA: Africa is dominated by culture and politics which limits scope for one organisation becoming representative of all. These proposals will attract more organisations from Africa, not just SA.

Australia: Congratulations to the MC and endorse the whole concept though the shared fee uplift is too low at 25% and 100% is preferred.

CF offered a final opportunity for delegates that had not spoken on this matter to do so.

Motion: To accept the new membership structure; the change from country-based to the proposed organisation-based structure. If this motion is not carried then all other related motions become void.  
Motion carried 17 – 3 with no abstentions.

SJ reiterated the membership criteria which are the same as under the country-based criteria, with the amendment that a subgroup of a blind society may join using the constitution and accounts of that blind society. CF invited comments and questions.

Netherlands: Propose to add to the procedure for new membership the additional criteria that an existing full member (in the same country) is asked for opinion and advice and has a veto right over the entry of the new member.

Motion: The MC submits for approval the new membership criteria as laid out in the document submitted by Stephen Jones.

Seconded: UK and Australia

Motion carried 18-2 with no abstentions.

Motion: Netherlands move to add that the MC is tasked with submitting to the next General Assembly additions to the procedure for new membership; the additional criteria that an existing full member (in the same country) is asked for opinion and advice and has a veto right over the entry of the new member.

Seconded: Greece, Spain

Motion defeated 12N-4 with 4 abstentions.

Both the Norway and USA representatives stated that the Netherlands proposal including the veto was unacceptable, but that consultation with an existing member in a country should still go ahead. This was agreed by CF and discussion on this subject will be carried forward in the working plans for the future.

Motion: The MC submits for approval the new membership categories as laid out in the document submitted by Stephen Jones. No delegate wished to speak further on this matter

Seconded: UK and Australia

Motion carried 19-0 with 1 abstention.

CF invited comment on the issue of introducing a vote-capping system, the proposal being that the MC would be charged with making a recommendation to the GA that RI impose a cap if it was felt that the number of voting members from a single country was inappropriate.

Ireland: Asked SJ to clarify the motion as it seemed a bit arbitrary and offered no protection in its current form. SJ responded that the MC would not make an arbitrary decision but would come to the GA with a recommendation. Detailed plans for how a cap might work have not been established and would have to be a topic for the future.

Norway: Similar concerns as Ireland, and would like to know what issues would be considered, eg size of country, nature of the organisations. Norway was supportive of the principle. Norway

proposed that the MC is charged with bringing detail to the next GA. SJ and CF agreed and CF proposed a rewording of the motion as follows:

Motion: The GA agree the principle of a vote capping system if there are too many organisations from one country and the MC is to present detailed proposals to the next GA.

Seconded: Australia and Sweden

Motion carried 17-2 with 1 abstention.

Action point: MC to prepare vote capping proposals for the next GA.

CF introduced the final motion in this section, regarding the fee structure for countries with more than one member. The MC had proposed a shared uplift of 25% per member, Ireland had proposed 50% per member, and the USA 100% (ie the same full fee for each member). CF invited comments and questions.

USA: Pointed out that at less than 100%, RI would be selling the vote at a discount, and the USA feels very strongly that this is undemocratic. Also, payment of the fee is an indication of an organisations sincerity.

Sweden: Expressed support for increasing the uplift to the minimum of 50%

Pakistan: Expressed support for an uplift of 100%, ie the full fee for each organisations. Agree with USA's comments. In addition this will act as a disincentive to fragmentation.

Norway: Supportive of the USA proposal for 100%, in addition all organisations should be treated equally.

Ireland: Understand the USA proposal but there concerned about seeking the full fee from all organisations in a country. Asked SJ to elaborate as to why 25% was proposed. In addition, increased income from fees should be used to fund growth, not a fee reduction. SJ responded that the 25% had been fairly arbitrary and aimed at lower and middle income countries, which are underrepresented in RI at present. For example, a fee reduction may incentivise additional

applications from India. SJs own view was that full fee is rather high and if it is voted in then flexibility may have to be shown in the future if it proves to be a barrier.

Motion: That if there are several member organisation in a country they will all pay the same full fee. This motion if carried will make the proposals that an uplift of 25% or 50% void.

Seconded: Germany and Pakistan (and others simultaneously)

Motion carried 12-6 with 2 abstentions.

In humour, the USA delegate pointed out he was glad the motion had been passed otherwise the USA would resign, wait for another organisation to join, and then rejoin at a much lower fee!

## **6.2 RI Officers Elections**

With the meetings agreement CF brought this item forward to give time to the ballot scrutineers, item 5 being deferred. Delegates were asked to vote (secret ballot) on 5 nominations for the 5 places on the MC, and the one nomination for President, for the coming 2 year term. Nominations were: For the MC; Fraser Alexander, Stephen Jones, Caiza Ramshage, Mariana Antoinetta Leopoldi, Claudette Medefindt, and for the President; Christina Fasser

## **5. Constitutional Amendments**

CF called on SJ to present proposals for amending the RI constitution to accommodate the changes to the membership structure already agreed. The amended constitution had been circulated with meeting papers as Appendices 04-1, 04-2 and 04-3.

SJ advised that two further minor amendments needed to be added; 4.2.1.1 to be amended by the addition of “or are a subgroup of a larger organisation that has a constitution” and 4.5.4 to be added stating “Associated organisations’ membership would have to be approved by the next General assembly”. Also, a proposal had been made earlier that Associated Organisations would have to pay fees. CF brought this motion to the vote first.

Motion: That Associated Organisations are brought within the fee structure, the detail of what fees should be paid to be included in the membership fee policy and approved by the next GA.

Seconded: Norway and Sweden

Motion carried unanimously.

Action point: SJ to write this further amendment into the constitution.

Action point: MC to bring proposals for appropriate changes to the membership fee policy to the next GA.

CF invited comments and questions on the proposal from the MC that constitutional amendments are also made to facilitate the changes to the membership structure agreed earlier in the meeting.

USA: asked that two further amendments were made to the constitution to take the opportunity to close two potential 'loopholes'. Firstly, referring to the minutes from Helsinki (Section 104) there was a need to clarify the date on which membership fees were due as 31<sup>st</sup> December each year, and secondly there was a need to prevent a delegate serving on the MC if his or her host organisation is not up to date with fees.

CF agreed that these amendments were sensible and agreed to defer a vote on the constitutional amendments until after lunch in order that delegates could consider these proposals. The meeting adjourned for lunch.

## **6.2 RI Officers Elections**

Over lunch the scrutineers had counted the votes for the elections. All of the above listed nominees were returned to the Management Committee and Christina Fasser was returned as President. CF accepted the Presidency and expressed thanks to the GA for continued confidence in her holding office.

## **5. Constitutional Amendments**

Continuing the discussions CF advised that the first proposal from the USA for further amendment to the constitution was not necessary, as this was covered adequately by the Rules.

In respect of the second USA proposal, this was formalised as follows:

Motion: That RI constitution is amended by the addition of a new second sentence to section 9.1.2 "Initial and continuing service on the MC by a member of the MC is contingent upon that member's sponsoring organisation being in continual compliance with the financial requirements pertaining to voting privileges of section 7.7".

No delegate wished to speak further on this matter.

Seconded: UK and Australia.

Motion carried unanimously.

Action point: SJ to write this further amendment into the constitution.

Motion: That RI adopt the constitutional amendments as presented in Appendices 04-1, 04-2 and 04-3, together with the two minor further amendments to section 4.2.1.1 and 4.5.4 described by SJ in his presentation.

No delegate wished to speak further on this matter.

Seconded: Australia and Greece.

Motion carried unanimously.

CF thanked the GA for dealing clearly with the tough issues of membership and constitutional change, and Stephen Jones for his hard work.

## **6. Elections**

CF called on Claudette Medefindt (CM) to present new members for election, under the new classifications.

### **6.1.1 Candidate Members**

CM advised that the Iranian RP Society would be in discussion with the MC over the coming term of office with a view to changing from current status as a Candidate Member to a Full Member

Four applications for Candidate Member status had been received.

(1) Taiwan RP Association, established in 2007, all documentation translated and complete, MC recommended that TRPA was accepted as a Candidate Member, and advised that they were aware of the fees they will have to pay. CM invited questions for the MC, the Taiwan delegation not being present in the room.

Switzerland: How many members does TRPA have? CM responded approximately 300, currently only PR patients but may extend to serve AMD patients later on.

Greece: Is Taiwan recognised by the UN? CF responded that RI now invites organisations rather than countries as members. We are able to discount the politics and recognise the organisation not the country. TRPA would be classified for fees in the same way as Hong Kong.

Motion: That the Taiwan RP Association is accepted as a candidate member and handled for the fee structure in the same way as Hong Kong.

Seconded: Australia and Switzerland.

Motion carried unanimously.

TRPA was welcomed as a Candidate Member of RI.

(2) Fundacion Argentina De Retinosis Pigmentaria (FARP). Documentation was received except SMAB papers. The MC proposed that provided these are in place within 2 months that FARP was accepted as a Candidate Member. CM invited questions for the MC, the Argentinian group not being present at this GA.

Norway: Is this a resurrection of the old Argentinian RP organisation or a new one, and how many members do they claim? CF responded that it was a different organisation but there are links, the Presidents know each other for example. They have some 9,000 members.

Motion: That FARP Argentina is accepted as a candidate member provided that the missing SMAB papers are submitted to RI by 31st August 2010

Seconded: Australia and Greece.

Motion carried unanimously.

FARP Argentina was welcomed as a Candidate Member of RI. In response to a request from CF, FARPE (Spain) agreed to support and advise FARP (Argentina), and to take them under their wing.

Action point: FARPE to make contact and offer support to FARP as a Candidate Member

Action point: FARP to submit SMAB papers to MC

At this point the delegation from Portugal joined the GA

(3) Retina India. All documentation was complete except the first financial year ended in September and accounts would not be submitted until November. CM took particular pride in presenting this group for election as she had been mentoring the group for some considerable time. CM invited questions for the MC, the Indian group not being present at this GA.

Norway: Where in India is the group situated? CF advised they are based in Mumbai but are a national group.

Switzerland: Is November an adequate time scale for production of the audited accounts? CF advised that the deadline had been readily agreed by Retina India

Motion: That Retina India is accepted as a candidate member provided that the first year's accounts are submitted to RI by 30th November 2010

Seconded: Norway and Greece.

Motion carried unanimously.

Retina India was welcomed as a Candidate Member of RI

Action point: Retina India to submit audited accounts to MC

(4) Retinitis Pigmentosa ASPL (Belgium). All criteria were met and all documentation was complete. Present was Viviane Hallet-Tordeurs, President of ASPL. CF invited questions and comments from the floor.

Greece: Queried as to whether ASPL served both Walloon and Flemish communities in Belgium. Viviane explained that the country was fully united and the organisation did not distinguish, CF reinforced this point.

Motion: That ASPL (Belgium) is accepted as a candidate member of RI

Seconded: Switzerland and Sweden.

Motion carried unanimously.

ASPL was welcomed as a Candidate Member of RI.

### 6.1.2 Interested Groups

CM advised that Fundalu RP (Chile) had submitted an incomplete application but had no accounts or SMAB yet.

Motion: That Fundalu RP is accepted as an Interest Group of RI

No delegate wished to speak further on this matter

Seconded: Greece and Norway

Motion carried unanimously.

Fundalu RP was welcomed as an Interested Group of RI.

### Reclassifications

CM affirmed as already discussed that Poland was to be reclassified as an Interested Group

CM affirmed as already discussed that Panama was to be reclassified as an Interested Group

CM affirmed as already discussed that Hungary may be reclassified as an Interested Group

3 existing members were eligible to be classified as Candidate Members under the new structure; the Danish Society for the Blind, Fundacion Retina Espana, and the Association for the Blind and Visually Impaired of Iceland.

Motion: That these three organisations may submit applications with all supporting documentation for reclassification as Candidate

Members by 31<sup>st</sup> December 2010. No delegate wished to speak further on this matter.

Seconded: Norway and New Zealand

Motion carried 17-1 with 3 abstentions

Action point: Danish Society for the Blind, Fundacion Retina Espana, and the Association for the Blind and Visually Impaired of Iceland to complete and submit applications for Candidate Member status.

CM advised the GA that Foresight Dubai has halted operations and is no longer a member, and asked that the GA recognise the contribution made by Foresight over recent years. CF reinforced this as did David Head (UK) who noted that Foresight had contributed GBP 250,000 by co-funding research at Moorfields Eye Hospital, London.

Motion: CF proposed that she writes formally to Katy Newitt with thanks and recognition for this work. No debate was felt necessary on this issue, after seconding by USA and SA the motion was carried unanimously by applause.

Action point: CF to write to Katy Newitt

CM advised that the interested group from Singapore will be asked to apply as an Associate Member as they are not patient led, but driven by the professionals in that country. Also that 14 other interested groups exist. (A full list of member (organisations!) in their various new categories will be issued with these minutes)

CM advised that Retina Belangen (Netherlands) has withdrawn their application for membership. The existing Netherlands delegation stressed that they felt there was a need for this type of information to be communicated to existing members in the country.

CF noted this request and will now include such information in future Presidents' Reports.

CF closed the session on membership elections and thanks CM for her work on this topic.

## *6.2 Retina International Officers*

This agenda item had already been completed as a result of timing changes

## *6.3 Special Recognitions*

CF advised that the MC was seeking the GA approval to make two awards recognising individual contributions to the work of Retina international.

**David Waldron** (Ireland): Was involved since 1998 and contributed in particular to work developing the website and RI youth work, and has had to retire from RI because of other commitments

**Rehan Shibli** (Pakistan): Was instrumental in the development of RI including looking after the finances and the finance committee.

Motion: The MC moves to recognise the contribution of David Waldron and Rehan Shibli, the work they have done and their dedication to Retina International.

Seconded: USA and Greece

Motion carried unanimously by applause

Action: Irish and Pakistani delegation to convey these awards to David and Rehan respectively

CF advised that the MC was seeking the GA approval to make two awards recognising four scientists' individual contributions to the work of Retina international.

Prof **Gerald Chader** (also Secretary of the RI SMAB) and ...

Prof **Joe Hollyfield** have both been involved since the inception of Retina International and have been instrumental in building networks and making scientific breakthroughs

Prof **Matthew LaVail** discovered the neuroprotective properties of CNTF and has been instrumental in progressing this line of research developing the potential first drug treatment.

Prof **Eberhart Zrenner**

Motion: The MC moves to recognise the contribution of Professors Gerald Chader, Joe Hollyfield, Matthew LaVail, and Eberhart Zrenner, for their contributions to Retina International and retinal research.

Seconded: SA and Germany (and others!)

Motion carried unanimously

## **7. Retina International Work Plan and Budget 2010 – 2012**

Previously circulated as Appendices 06 and 07 respectively.

### *7.1 Work Plan*

CF invited questions and comments on the 2010-2012 Work Plan.

Ireland: Described the plan as excellent and ambitious. The MC has been struggling with limited resources and consists of a small number of long standing members. Thought needs to be given to the administrative and executive structure. RI has achieved a lot and contributed in no small part to retinal research. Need now a wider reach, influence and impact as well as anticipating more policy work in the future, and Ireland cannot see how this will be done with the current (voluntary) structure.

Ireland: Would therefore like to propose that a sub-committee be set up to explore and seek funding for the possible appointment of a paid full time executive to work under the President and MC.

CF welcomed this proposal very much and noted that future work demands a professionalization of RI as time and resources from a volunteer force are very limited. CF invited comment and questions on this proposition.

UK: Strongly supported this initiative and noted that it reflects recent changes at the British RP Society.

SA: Strongly supported this initiative and noted the long hours currently worked by CF on a volunteer basis.

CF: Reminded the GA that she would not be present for ever. In her capacity as President she sees challenges ahead and welcomes the

initiative and would like to see proposals presented in 2 years time at the next GA

Norway: Reiterated that CF will not be present forever and endorsed the proposal. Norway also noted that such a subcommittee will need also to consider succession planning and the physical location (host) for the executive.

Motion: That a sub-committee be set up to explore and seek funding for the possible appointment of a paid full time executive to work under the President and MC.

Seconded: UK and Australia

Motion carried 20-1 with no abstentions.

Action point: MC to establish subcommittee and report at next GA with proposals for creating a paid executive

CF asked for volunteers for the subcommittee, Ireland and Switzerland volunteered and the UK offered to advise the group. The Irish delegation circulated copies of a "Paper on the Potential to Establish a Professional Secretariat to aid the Development of Retina International".

Motion: That the GA accepts the work plan as submitted.

Seconded: Ireland and Sweden

Motion carried unanimously.

## *7.2 Budget*

CF invited questions and comments on the 2010-2012 budget, noting that in view of the underlying economic situation it is proposed that the increase of 15% is (exceptionally) not made for this period and provisional calculations for the fees for next year indicate a slight reduction.

Pakistan: Noted that comparisons with previous years' figures would be useful in the figures presented, can this be provided in future? Observed that costs have been trimmed significantly, but concerned that this may not be realistic. Noted that the resulting surplus or deficit should be recorded at the foot of the budget proposals.

Brazil: Observed that 2012 expenses are higher than for 2011 because this is a congress year.

Norway: Observed that more detailed notes in the accounts would be helpful in explaining year on year changes.

Motion: That the GA accepts the budget as submitted.

Seconded: Pakistan and Switzerland

Motion carried 20-0 with 1 abstention.

## **8. Retina International Conferences**

### *8.1 2012 (Germany)*

Markus Georg gave a presentation of the key points regarding the 2012 event (previously circulated as Appendix 08) and invited delegates to attend in Hamburg 11 July 2012 – 15<sup>th</sup> July 2012. The event had been moved from Koln due to difficulty securing a Koln venue. The venue is accommodation and conference all under one roof and is very accessible and the Germans are expecting attendance of approximately 1,000. A youth meeting will be included.

CF invited questions and comments.

Netherlands: Welcomes in particular the presence of a youth programme

Spain: Requested that Spanish translation is provided at the event. CF noted that translation is very expensive at about EURO 7,000 per language.

CF complimented the German delegation on their plans and wished them well for the development of the event.

### *8.2 2014 (France)*

CF advised that a submission had been received from Retina France to host the event in Paris in 2014. This had been previously circulated as Appendix 09.

The French delegation gave a presentation of the key points regarding the 2012 event (*Minute note, this item was not audio recorded as the microphones were not used*)

Retina France has about 20,000 members and a budget of EURO 2.2m of which EUR 1.4m is invested in research. Funding comes from members and from various high-profile events. Retina France hosted the conference in 1994 which was very successful. 2014 will be “even better than in 1994” with a projected delegation of 1,000 and a comprehensive scientific programme, including, it is hoped, news of clinical gene therapy trials in Paris. The venue will be the same as in 1994. France offers good wine, good food, good company, and good science!

In response to points raised in open discussion, the French delegation advised that plans are not well advanced at present but the desire for a youth programme was noted, and that the event will take place in July 2014 but the exact date had not yet been set.

Motion: The MC moves to welcome and accept the application from Retina France to host the 2014 Retina International Congress in Paris.

Seconded: Greece and Australia.

Motion carried unanimously.

## **9. Marketing**

### *9.1 World Retina Day (WRD)*

CF advised that she understood some delegates had asked that World Retina Day was brought forward . She asked Frazer Alexander (NZ and MC) to comment. FA advised that WRD is in his view RIs best opportunity to raise awareness of retinal research and to raise funds.

CF invited further comments on WRD

SA: added that they have had some success in getting a pharmaceutical company to support an awareness month that starts

with WRD. Sponsorship in place includes access to a PR company and has been very successful

Ireland: observed that AMD week has “taken over” in some countries and RI should either work more closely with the AMD Alliance or set a different date. CF agreed and noted that an agreement with the AMD Alliance means that it should be Retina Week not AMD week.

No actions arising

### *9.2 Retina International Website*

CF pointed out that the website has been revised but it was important that member organisations provide details of events and other content, as it will only be as good as its content. She asked that all members provide this to the RI admin team as that team do not have the resources to chase or research this information.

Action point: Member organisations to ensure RI staff are notified of major events and news for inclusion on the RI website.

CF invited further comment or questions regarding the website.

SA: Expressed thanks to RI for the scientific content but to point out that an important recent paper on the influence of Lutein and Vitamin A had been omitted. This type of information is crucial to members.

USA: Noted that the RI charter includes the dissemination of information so all member organisations should be required to provide information and disseminate it onwards. On the issue of dissemination of information the USA advised of a Vision Conference in Baltimore in June 2011 at the same time as the 40<sup>th</sup> anniversary of Foundation Fighting Blindness. Please can this be included on the RI site and disseminated by others.

Action point: USA to provide details of the 2011 Baltimore Vision Conference for onward dissemination

## **10. Regional Activities**

There were no items for discussion under this agenda item.

## **11. Miscellaneous**

CF invited items of any other business from delegates.

Iceland: advised that Nordic countries RP groups meet regularly, and had identified a need for their ophthalmologists to keep up to date with developments. Thus a conference is taking place in Reykjavík on 7th August 2010 and will include an RP Symposium.

Ireland: European countries should note that under EU plans announced in June 2009 National Plans for Rare Diseases need to be established in all member states by 2013. This will lead to a number of conferences, events and workshops across Europe and RI organisations should take the opportunity to participate in and influence these events and the development of the Rare Disease Plans. CF endorsed this and will disseminate information to be provided by Ireland on the events as they become available.

Action point: Ireland to provide event details to RI as available for onward dissemination

Norway: Expressed thanks to the Irish delegation for the work on Rare Diseases but noted that in Norway RP is not classified as rare. Should be interesting to see how the Norwegian government deals with this.

SA: Expressed thanks to CF, the Italian hosts, and the RI team for a successful GA and wished them well for the rest of the congress.

CF concluded the GA 2010 by endorsing this and by thanking all the delegates for attending and taking part and wishing everyone a successful upcoming congress.

END