



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

Retina International General Assembly 2012

Hamburg (Germany)

Thursday, July 12th, 2012

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Hamburg (Germany)

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Room: Spiegelsaal

APPENDIX 03-1

3.1 President's Report and MC Reports 2010-2012

Table of contents

1. Introduction	pg 3
2. Objectives and division of labour	pg 3
3. Term of office report 2010 – 2012	pg 3
3.1 Introduction	pg 3
3.2 Membership, Governance and Constitution	pg 4
3.2.1 General Information	pg 4
3.2.2 Membership sub-committee report	pg 4
3.2.3 Governance report	pg 6
3.3 Research	pg 6
3.4 Communications and marketing	pg 7
3.4.1. Clinical trials- patient Statement	pg 7
3.4.2 World Retina Day	pg 7
3.4.3 Cultivating new members via circulating ritzman reports	pg 7
3.4.4 Asia-pacific Academy of Ophthalmology- patient involvement	pg 8
3.4.5 Retina International Website	pg 8
3.4.6 Scientific Newsletter	pg 8

3.5	Retina International Conferences	pg 10
3.5.1	Stresa (Italy) 2010	pg 10
3.5.2	Germany 2012	pg 10
3.5.3	France 2014	pg 10
3.5.4	Future conferences	pg 10
3.6	Youth	pg 11
3.7	Retina International Operations	pg 11
3.7.1	Funding and books	pg 11
3.7.2	Assistant	pg 13
3.7.3	Travel activities of the president	pg 13
3.8	Support of research applications	pg 13
3.9	AMD Alliance	pg 14
3.10	Eurovision Net	pg 15
3.11	Retina International Scientific and Medical Advisory Board (SMAB)	pg 15
4	Reflections for the future	pg 16
5	Acknowledgements	pg 17
Appendix 1	List of member organisations and membership status	pg 19
Appendix 2	Travel activities of RI president 2010-2012	pg 21

1. Introduction

This report covers the activities of Retina International from July 2010 to July 2012. The General Assembly (GA) in Stresa elected the following officers to the Management Committee (MC):

Christina Fasser (President)
Fraser Alexander (MC)
Stephen Jones (MC)
Maria-Antonietta Leopoldi (MC)
Claudette Medefindt (MC)
Caisa Ramshagen (MC)

This report covers the activities of the Retina International president as well as of those of the different MC sub-committees.

2. Objectives and division of labour

The primary objective of Retina International is to promote research that will lead to the treatment and cure of Retinitis pigmentosa, Usher Syndrome, Macular Degeneration and allied retinal dystrophies. All Management Committee activities should be viewed in the light of this objective.

Major areas of focus of the Retina International MC were defined as:

- Support of activities that focus on finding treatments or a cure for retinal dystrophies
- Information dissemination
- Membership development
- The biennial international conference
- Organisational efficiency
- Marketing

The aim of the sub-committees was to share responsibilities and work required by the organization. As much as possible, the sub-committees followed the work plan accepted by the General Assembly 2010 in Stresa.

3. Term of office report 2010 - 2012

3.1 Introduction

At its first face-to-face meeting, held in Stresa, the MC established an ambitious work plan that gave greater responsibility to individual MC sub-committees. The chairs of the different sub-committees were asked to include in their committees non-MC members in order to improve inclusion

of our member organisations and to make use of the precious knowledge among our membership.

Once again, our call for volunteers met with minimal response, reflecting the fact that potential candidates are very involved in their home organisation and that local work takes precedence over RI obligations. This report is structured along the work plan accepted by the GA 2010 in Stresa.

In June 2011 a mid-term meeting Was held in conjunction with the Vision Conference in Baltimore USA, where the MC reviewed the strategy and decided, how to get the feasibility study done to establish a Retina International Office.

3.2 Membership, Governance and Constitution

3.2.1 General Information

Retina International maintains regular contact with its members through the sharing of research information and related topics. The members of the MC and the president take every opportunity to meet with representatives of member organisations to mentor and to maintain personal contacts. Also, whenever possible, the president accepts the invitation of member organisations to visit, coach the leaders of the organization and to speak at their conferences and special events. However, the primary contact with member organisations is conducted by email.

Emphasis is given to nurture and contact with new and developing members in order to provide them with advice and the support needed to establish a strong organisation of patients with retinal degenerative diseases. At the GA 2012, we will have the pleasure to welcome at least four (4) new organisations into the RI family.

3.2.2 Membership Sub-Committee report

Members: Claudette Medefindt.

REPORT ON MEMBERSHIP TO RETINA INTERNATIONAL

May 2012 by Claudette Medefindt

MEMBERSHIP APPLICATIONS:

1. Full Membership.
3 members have served the 2 year probationary period and are now applying for full membership.
 - a) Taiwan RP Association
 - b) Retina Pigmentosa ASBL (Association Belge Francophone de la rétinopathie d'origine génétique- Belgium

- c) Blindrafelagid, Icelandic organization of the visually impaired (BIOVI), on behalf of Retina Iceland.
RECOMMENDATION: that these 3 organisations be accepted as an Full members of Retina International;

Candidate Membership.

- Fundacion Argentina de Retinosis Pigmentaria [FARP] – Argentina
- Fundacion Lucha Contra la Retinitis Pigmentosa [FUNDALURP] - Chile

The Chilean Organisation was provisionally accepted as a Candidate member at the 2010 Congress in Stresa but failed to comply with the terms as agreed by the GA. This organisation has now complied and is eligible for Candidate Membership.

FARP is one of 3 patients support groups active in Argentina. They have fulfilled the criteria for Candidate membership.

RECOMMENDATION : The MC recommend that these 2 organisations be accepted as candidate Members.

Communication with various other organisations and individuals have been maintained and a constant climate of encouragement and mentorship is ongoing. The President and the MC member responsible for membership Claudette Medefindt would like to acknowledge the efforts of KP Tsang, Maria- Antoinette Leopoldi, Stephen Jones, Rainald von Gyzicki and Alan Kahn for their efforts in membership development.

INTERESTED ORGANISATIONS AND GROUPS.

We continue to encourage all interested groups to affiliate to Retina International and a marketing drive is underway. With great pleasure we learned from the official establishment of the RP committee in Mainland china and a first personal contact was established in Geneva in April 2012.

EMAILS REPLIES TO RETINA INTERNATIONAL

Individual Emails were sent to patients from 20 countries:

Australia, Bangladesh, Brazil, Congo, Ecuador, India, Kenya, Morocco, Mozambique, Namibia, Nigeria, Pakistan, Rwanda, Saudi Arabia, Tanzania, Ukraine, United Arab Emirates, United States, United Kingdom, Zimbabwe and 6 queries from Unknown Countries that did not respond to our emails.

MEMBERSHIP STATUS

Full members : 23

Candidate Members:6

Interested groups: 14

Associate member: 1

3.2.3 Governance report

Member: Stephen Jones

- a) The main issue relating to governance is the proposal to restructure RI and create a secretariat. This is the subject of a separate paper submitted to the GA.
- b) It was agreed at the GA in Stresa 2010 that RI would change to an organisation based membership structure. This required certain changes to be made to the RI constitution and business rules. A draft constitution had already been submitted to the GA in Stresa and the few changes stipulated by the GA were incorporated after the conference and the revised constitution has been on the RI website since that time.
- c) In addition to the incorporation of the membership document in the business rules, referred to above, it was decided that an attempt should be made to improve the presentation of the business rules in one document. Over many years various additions have been made to the business rules which had become rather complicated and cluttered. Therefore, an attempt has been made to clean up and improve the presentation of the rules in one draft document (see document GA12-appendix 06-1 and 06-2)

3.3 Research

The main task of the research committee is to work in close cooperation with Professors Gerald G. Chader, Joe Holly field and E. Zrenner to organise the RI SMAB meetings at the ARVO meeting in Fort Lauderdale. The agenda has to be developed, the speakers invited and the meeting location and setup organised. We are proud to report that this meeting has developed such a high reputation that invitations are highly sought and that we have to limit attendance.

The minutes of the SMAB provide the RI membership with a valuable insight into ongoing research and treatment trials that would not be available elsewhere.

Additionally, substantial work has been put into lobbying for EU funding and within the Eurovision net programme. Its focus is to place vision on the European agenda and to bring all stakeholders in vision research in Europe onto a single platform. Retina International is participating actively and was funded for this purpose.

Whenever possible, the president represents and advocates for the needs of patients with retinal degenerative diseases. Among other opportunities,

the president had been invited to give a talk at the Novartis Boston Research Section and to QLT.

3.4 Communication and marketing

Member: Fraser Alexander

TERM 2010 -2012

3.4.1. Clinical trials- patient Statement

Following general agreement from the MC in 2010, I undertook to come up with a document for RI's website that gave our patients some idea of what is involved with clinical trials and some of the relevant issues for patients as they consider participation. With guidance from the information contained on www.clinicaltrials.gov, I worked with Claudette, Christina, Stephen and others to make it RI-relevant. There exists a need to update this document from time to time to ensure accuracy, currency and readability and I expect to do this in co-operation with the RI SMAB.

3.4.2. World Retina Day 2010 and 2011

In drafting the 2010 world retina Day press release with the theme "time to play your part", I tried to emphasise that patients needed to show leadership around the world and needed to do so on a number of fronts. Advocacy, being part of scientific and medical investigations, lobbying for public funding of effective treatments etc. again working with the MC we released the statement in September.

3.4.3 Cultivating new members via circulating Ritzman reports and the "Case for joining RI" document among Pacific rim and Asia prospects.

In speaking with Graeme Banks from retina Australia and looking at the WBU website to get an idea of first-contacts in countries we may not have had previous contact, I identified:

China Association of the blind

National council of the blind Malaysia/society of the blind Malaysia

Fiji society of the blind/United blind persons of Fiji

Indonesian blind Union

Korean blind Union

Association of the blind Papua New Guinea

Philippine blind Union

Independent society of the blind Singapore

Thailand Association of the blind

Vietnam blind Association

Bangladesh National Society of the Blind

In June 2012 we will have all relevant information on these organisations and a list of disease/disorder specific organisations such that we can email a tailored approach. for the organisations we identify as being the closest relatives(in terms of their objectives) , I have now drafted and gained MC approval for an email(translated where possible) that draws on our "why become a member of RI?" document, and explanation of what we want to achieve and why our cause is increasingly important to people with retinal disorders. for the larger organisations some follow up phone calls to these messages will be made (we will try to ascertain who the correct person is to call, best time etc) and take it all from there.

Our selection and message is designed as to not impinge on the work of the World blind union. For such reasons, I have contacted Marianne Diamond about our approach but a renewal of this could be appropriate.

3.4.4. Asia-pacific Academy of Ophthalmology- patient involvement

Through the Chair of the organising committee for the APAO 2011 Meeting in Sydney, Professor Charles Mcghee, I obtained an agreement that APAO would promote retina International at upcoming meetings and within APAO publications. This will begin with the 2012 meeting in Busan, south Korea.

As a member of the Choroideremia Research Foundation, I have undertook to write an article on the 17 RI world congress in 2012 and will continue to promote RI here as appropriate.

Along with retina Australia President Graeme banks and retina victoria's Leighton boyd we will continue to progress a number of initiatives such as patient database collaboration, promoting RI in the region, medical research funding application support and conference invitation agreements).

3.4.5 *Retina International Website*

The website of Retina International has been greatly improved; member data is updated whenever necessary and the President's office is notified. The website needed to be restructured (introduction of a new CMS). This was done during 2011 and 2012. This new system allows us that the secretaries are able to upload and maintain the website without need to have the support of technical staff (costly).

3.4.6 *Scientific Newsletter*

Report by: Dr. Markus Preising, Giessen, Germany.

Since 1998 Retina International supports its scientific homepage (Retina International Scientific News, RISN) which was always well accepted especially by clinicians. The site provides a set of detailed data collections on retinal disorders which grew each year with the growing knowledge in retinal disorders. The current site contains over 250 pages.

The introduction of the novel content management system (CMS) of the Retina International site requires the transfer of these pages into the CMS system which requires a major effort.

The central entry point is the disease loci table which refers to subpages focussing on detailed information on disease groups like Retinitis pigmentosa, Leber congenital amaurosis, or cone and cone-rod degenerations.

The mutation databases were one of the highlights of the RISN. Efforts by several consortia either for specific genes or in general established mutation databases at high technical standard which meanwhile provide a service of higher information standard. Unfortunately, these databases are usually either published as full version with costs or with incomplete content for free access or within data collections unsuitable for daily clinical work. To provide full coverage of data and to cope with the developments in database technology and information content an increase of manpower is necessary that is not covered by the available funds. Therefore, the mutation databases shall change the focus to genes with incomplete coverage in other databases.

An important part of the mutation databases are the elaborated sequences which are WORD files summarizing known mutations onto a reference sequence of a retinal degeneration gene. This service shall be expanded to more genes as well as the graphical work up of the mutation specific datasets like for rhodopsin or bestrophin which provides some ideas of the functional impact of the mutations.

The protein databases including the editorial notes shall be put more into focus and novel pages shall be created explaining the interaction of the gene products involved in retinal pathways and networks like the visual cascade. This includes the notes from the editor database where published data on the applied scientific methods and the function of the retinal proteins are extracted from publications. This database has some advantage over other databases since the user does not need to copy a publication to get an overview on the content which usually cannot be extracted from the abstract. In this regard the protein databases are useful for scientists and patients.

The provided funds will be used for travel expenses of the editor in chief to the SMAB meeting AT arvo and for the salary of collaborators supporting

the editor in chief as well as costs for software, access charges, and consumables at the office (2013 – 2015).

Travel costs	annually	3500 CHF
Manpower	annually	10000 CHF
Office	annually	500 CHF
Total costs	annually	14 000 CHF

I hope that we can proceed with the project.

3.5 Retina International Conferences

3.5.1 Italy 2010

The Retina International Conference was held successfully in July 2010 in Stresa (Italy). The conference was excellently organised and a great success with 550 participants. The format of the conference was unique for Italy and the contact patients and scientists was extremely appreciated..

3.5.2 Germany 2012

The GA 2008 granted Germany the conference for 2012. The conference is to be held in Hamburg Germany, just prior to the RD 2012 meeting near Munich. The conference benefits thus that the most important researchers in the retina field are all in Germany. Local scientific host is Prof. Dr. Andreas Gal and Prof. E. Zrenner who established together with Franz Badura and the RI president a remarkable programme. We are convinced that the conference will be a great success.

When writing the report, the president is working with the organisers on developing the conference program and setting up the conference logistics.

3.5.3 Paris 2014

Retina France has established a organising and programme committee and has already booked the venue at la Cité des Sciences. For all that have attended the Retina International conference in 1994 will know the place and venue. The conference agency is chosen and the organising committee will be set up on May 12th, 2012. A formal report by Retina France will follow at the General Assembly 2012.

3.5.4 Future conferences

A major task of the President is to be on the constant lookout for member organizations to host the biennial RI conference. It was a long-time strategic goal to reach out to the Chinese population. With the entrance from Retina Taiwan a first step was made. In March 2011 Stephen Jones

and the president were invited by the Government of Taiwan in order to evaluate a future possibility that Taiwan is hosting a Retina International conference. This travel was very successful and we were able to see that Taiwan has the capacity and facilities to host the conference. We are very glad to announce that Hong Kong and Taiwan together are applying to host the Retina International Conference 2016.

In April 2012 the president met with K.P. Tsang from Hong Kong and with Yiah le le from the Chinese Retina Committee and was assured that the conference was most welcome and that it would be absolutely possible for patients from mainland China to travel to Taiwan to attend the conference. Since fall 2011 all respective restrictions had been lifted.

3.6 Youth

Member: Caisa Ramshagen

During 2010 there was a call sent out to all RI organisations to come back with 2-3 youth delegates from each organisation. This call was answered by 11 countries, and a total of 17 delegates have been named. In order to make it possible for all members to communicate there was a mailinglist set up for the group. The communication on the list have however been scarce, maybe due to the technic, maybe the communication channel should have been a facebook group.

During the Retina International conference in Hamburg there will also be a youth program the 10 - 15 July. The youth meeting has been arranged by Philipp Mansfeld and Markus Georg from Pro Retina Germany. The program includes sports activities suitable for visually impaired, visit to dark museum and university clinic among other activities.

If there after the the Youth meeting in Hamburg is enough participants interested in participating and arranging youth meetings then Retina International shall try to encorage the commitment and encourage the organisations that will arrange the comming RI conferences to fascilitate a youth meeting in connection with the RI conferences. It is also important that the RI member organisations try to involve youth in there local activities.

3.7 Retina International Operations

3.7.1 Funding and books

The budget of Retina International includes three major items:

- Basic running costs (phone, mailing, stationary, travel costs)
- Costs of assistants
- The Retina International Scientific newsletter

In Rio de Janeiro was decided that the fees allocated could only be increased by 10 %. This means that the running costs of Retina International are at present relatively spoken frozen. The only remedy is to acquire new members. Fortunately, we have new organizations applying for membership in 2010 and, hopefully the new proposed membership structure will attract new members. The more members we have the less the fees will be.

Since the implementation of the current membership fee rules, by the end of 2011, most members have paid up their fees and are in good standing with Retina International or have an agreed down-payment plan. Only one organisation had to apply to get a down payment plan. This is a major effort by our membership in view of the present finance crisis.

Despite this good balance, we must note that most member organisations still have to be reminded several times and very often the deadline of May 31st, the due date, is not respected.

However, we are happy to report that fundraising efforts have been successful; additional funds through personal donations and through participation in European projects were made available to Retina International.

The net capital of RI is healthy at present. Therefore, the MC and the finance committee had suggested that the budget 2011/12 was exceptionally not be increased by the additional amount of 15 % thus helping to maintain the fees at the present level.

The MC was sensitive to the fact that many of our member organizations are facing difficult economic times. However, for the budget 2013/2014 we will have to apply again the 15 % increase.

In Rio the GA decided that the fees of a member organisation could only be increased by 10 % or decreased annually by 5 %. If a member organisation shifted from one level to another, it takes them several years to be in the right group. Apart from the very difficult handling, this seems incorrect towards the members that are moving from candidate membership to full membership and have to phase into the new higher rank within 4 years. The MC will make a respective motion to the General Assembly 2012 in Hamburg.

The Stresa GA has decided that we should provide a transfer to accrued accounting. However, because of lack of capacity and in view that with the new office anyhow a new accountancy system will have to be implemented, the president has postponed this task.

3.7.2 Assistant

The main tasks of the assistants (Rita Filippini and Daniela Capelli) were:

- Bookkeeping
- Financial administration
- Correspondence
- Dissemination of information
- Retina International archives
- Retina International database
- Retina International website changes (addresses)

Please note that an increasing number of members also means an increasing number of administrative tasks and correspondence.

The time allocated to staff is the absolute minimum and the president is still required to do a lot of the secretarial work herself. In order to cover actual needs a 50% support instead of 30% is necessary. Members would have an easy possibility to help to save assistant's time and funds by paying in time the fees and sending us their documentation and address changes without prior reminder.

3.7.3 Travel activities of the president

Participation in meeting and conferences increases the visibility of Retina International. During the term of office the president committed to the following travel activities:
travels abroad of 76 days

The most important travel commitments were:

ARVO 2011

Visit to Taiwan 2011

Visit to India 2011

Visit to Chile 2011

ARVO 2012

List is added to this report.

3.8 Support of research applications

MC members were actively involved in preparing several applications for research support by the European Union. This is a difficult process and required a lot of effort by researchers and other persons involved. Even if these projects are only partly successful, they will have had the advantage of bringing researchers together to discuss common research projects. This

process was very fruitful and continued on other levels. In all these efforts, the Retina International SMAB played a major role. In Europe, the chair of the SMAB, Prof. E. Zrenner, and Prof. José Sahel as well as Prof. A. Moore are playing a major role in bringing researchers together and making things happen.

The respect that is paid to Retina International by funding agencies is reflected in the fact that RI is asked to support grant applications and we can see that applications supported by Retina International are successful.

The Eurovision Net Programme is ending by March 31st, 2012. It brought together the European Vision Research Community and made the Vision Research visible on a European level.

3.9 AMD Alliance

In July 1999, Retina International heard about the creation of AMD Alliance International. One of the founding members of this organisation is the Foundation Fighting Blindness. As the leading umbrella organisation promoting research into retinal degenerative diseases, it seemed important that Retina International should be part of this new organisation and try to influence it not only to promote awareness of AMD itself but also of the fact that AMD requires increased research funding in order to find a cure for this disease.

The mission of AMD Alliance International is:

- To generate awareness and understanding of age-related macular degeneration, to promote the importance of education, early detection, knowledge of treatment and rehabilitation options
- To preserve vision and improve the quality of life of individuals affected by Age-related Macular Degeneration

Initial target audiences and focus areas are:

- General Public/Senior Community/Caregivers and Support Groups/Media
- Medical Community/Insurance Payers/Government Decision Makers/Media;
- Current/Future AMD Alliance Members (Seniors & Vision Organisations)

Retina International became an AMD Alliance board member and actively influenced the Retina Week policy by encouraging its member organisations to cooperate with local events.

AMD Alliance undertook a review in order to streamline decision making and thus enable the organisation to react quickly to new developments. First discussions are under the way and the member organisation meeting in September 6th, 2012 in Milano will decide upon after prior consultation with the member organisations.

Retina International will monitor the development of this organisation very carefully and encourage members to take part, thereby actively guiding the focus of this organisation into our own areas of interest, i.e. to support research in order to find a cure for AMD as well as to ascertain access to treatment for patients with AMD.

A number of our member organisations became member of AMD Alliance International and are also members of the board (France, Hong Kong, FFB, Germany, Ireland, South Africa and Retina International).

3.10 Eurovision Net

Retina International co-operated in submitting a grant called Eurovision-Net" whose main objective is to bring all the players in eye research together in Europe in order to promote the needs of vision research and ophthalmic health within all European countries. In December the first European-Vision summit was held in Interlaken and on 16th April 2008 the Retina International president hosted the kick-off meeting in our offices in Zurich. Within the patient package a first review of existing patient organisations was carried out. However, I am sad to report that not all Retina International member organisations filled in the questionnaire and did therefore not benefit from the additional opportunity of visibility to the European vision community. A newsletter will be established giving news on different research results. In June 2011 a hearing was organised in Brussels in order to showcase the importance of vision research in the framework of the healthy aging community in Europe.

3.11 Retina International Scientific and Medical Advisory Board (SMAB)

The Retina International SMAB consists of two representatives of the national medical and scientific advisory boards of full members. The SMAB meets annually during the ARVO meeting in Fort Lauderdale. Under the leadership of Prof. J. Hollyfield and Prof. E. Zrenner, it has become a real place of exchange and plays an important role in updating Retina International members on the development of research in the field of retinal degenerative diseases. Furthermore, the Retina International SMAB plays an important role as advisor to the organisers of the Retina International Conference.

4. Reflections for the future

Retina International is a growing organisation and developing successfully from being an informal organisation to becoming more structured with rules and regulations. This transition is difficult and needs careful attention. Broadening the scope of Retina International also means bringing in new organisations with different cultures and working rules. However, in my opinion too much time is spent on budget and rules. These being the basis for good governance, they should not become the focus point of action. I sincerely hope that the General Assembly 2012 opens the way of a professional office and CEO for Retina International thus having a person full time available attending to all the daily challenges.

Retina International is in a very important phase of its existence: A number of clinical trials in humans have already begun and soon a number of new trials will follow. Treatments are not there yet, but they are clearly on the horizon. This means for us to prepare ourselves very carefully by:

- Influencing treatment trials in a way that they will have meaningful results
- making sure that the right patients for the right trials are found
- knowing the regulatory framework for introduction of new treatments
- lobbying health authorities that all patients with a retinal degeneration have the right to an early and precise diagnosis including genetic diagnosis if they wish

Retina International has a clear-cut mission statement and has to live up to its expectations.

The time is excellent, but no time to sit back! We will have to foster all our efforts to face the following challenges:

- Find the missing genes: The technology and strategies to find new genes have increased enormously. Today more than 205 genes are identified that cause inherited retinal degenerative diseases covering probably slightly more than 60 % of all cases. The technology exists that the missing genes might be found within the next 5 years. However, funding agencies do not believe finding new genes to be an innovative research approach and therefore financial support is difficult to find. The first modulating genes are found and show how important they are in predicting the cause of the disease.
- Bring research from the university laboratory into the laboratories of the pharmaceutical industry: Clinical trials are very expensive. Therefore, it is important that we face the future and develop strategies to do lobbying among health governments. One of the challenges will be to

work for both: AMD and RP. Special attention will have to be paid to avoid the possibility of potential RP treatments turned into AMD treatments alone because that disease promises more profit to the companies and shareholders.

- Prepare the patients: The first clinical trials and treatments - focus on patients with inherited retinal diseases. In order to have the best possible access to treatments for inherited forms of retinal degenerations, patients have to be identified and informed and co-operation with organisations of rare-diseases improved. A number of countries have installed a plan to promote rare diseases and it is important that inherited retinal diseases are included.
- Learn how market access of drugs is working: In order to be able to make sure that future treatments are available to the potential patients in time, we have to gather the expertise how drugs access the market, how the health market is regulated and how the health insurers cover the costs involved.
- Member organisations should actively promote reliable and updated patient registries where they not exist
- Member organisations should call on their departments of health in Government to pay for the genotyping and phenotype and for the registries being the base for access to future treatments
- Improve cooperation among members - in order to face the challenges, co-operation among the different members must be improved. Science is not restricted to national borders or continents.

5 . Acknowledgements

I would like to express my sincere thanks to the members of the Management Committee without whose assistance and encouragement the running of Retina International would be impossible. I would also like to express my special thanks to Dr. G. Chader who was instrumental in organising the Retina International SMAB meetings as well as in the dissemination of scientific information. Furthermore, the Foundation Fighting Blindness contributes generously to promote research in organising meetings and opening its doors to researchers from other Retina International member organisations. I also would like to express our sincere gratitude to Professors Sahel, Zrenner and Webster and especially to Dr. Thomas Wheeler-Schilling for their endeavours within Eurovision-Net programme that is bringing vision on the agenda of Europe.

Our sincere thanks go also to the Scientific and Medical Advisory Board and its two chairmen, Prof. E. Zrenner and Prof. Joe Hollyfield, for their help and willingness to assist and support our endeavours. We wish to acknowledge the efforts made by all researchers involved in the preparation of proposals to the European Union and congratulate them on their success.

I wish to acknowledge the Swiss Federation of the Blind and Visually Impaired; who provide us with our facilities at no cost and allow us to utilize their infrastructure. I also wish to thank the associate members for their contribution to the fee. Thanks to the educational grant by Richard Crump we will be able to finance part of the travel costs for new member organisations attending the first time a Retina International Conference.

Last, but not least, I would like to thank all Retina International members for their efforts over the last two years. It is an exciting time to work for our cause and I am convinced that one day we will achieve our common goal to find a cure for RP and other retinal degenerative dystrophies!

Christina Fasser
President, Retina International

Zurich, May 25th, 2012

Appendix 1 to president' s report 2010-2012

Member Organisations

Country	Status	name of organisation 1	last update	Total members	Patients	Donors	Others
Australia	FM	Retina Australia	2008	900	Total 900	Total 900	Total 900
Brazil	FM	Retina Brazil	none				
Canada	FM	The Foundation Fighting Blindness - Canada	2011	25'200	3700	23'000	0
Finland	FM	Retina Finland	2008	625	546	0	79
France	FM	Retina France	2007	16457	9485	6972	0
Germany	FM	Pro Retina Deutschland e.V.	2011	5782	4589	568	625
Greece	FM	Hellenic Retina Society (M.E.A..)	2011	450	440	10	0
Hong Kong	FM	Retina Hong Kong	2011	684	527	109	48
Ireland	FM	Fighting Blindness	2008	28580	580	28'000	0
Italy	FM	Retina Italia (Onlus)	2007	13	0	0	13
Japan	FM	JRPS	2011	4027	3800	131	96
Netherlands	FM	Retina Nederland	2008	1'191	1027	124	40
New Zealand	FM	Retina New Zealand Inc.	2010	370	350	30	20
Norway	FM	Retinitis Pigmentosa Foreningen i Norge	2011	691	658	0	33
Pakistan	FM	Pakistan Foundation Fighting Blindness	2008	2890	2800	90	0
Portugal	FM	Associação de Retinopatia de Portugal (ARP)	2011	1555	1357	198	0
South Africa	FM	Retina South Africa	2011	2272	1795	55	477
Spain	FM	FARPE	2011	7673	7000	598	75
Sweden	FM	Svenska RP-Föreningen	2009	540	500	0	40
Switzerland	FM	Retina Suisse	2011	1248	968	108	172
UK	FM	RP Fighting Blindness	2011	3009	2518	491	0
USA	FM	The Foundation Fighting Blindness Inc.	2011	491'891	122889	242214	369002
Belgium	CM	Retina Pigmentosa ASBL	none				
Iceland	CM	Retina Iceland	none				
India	CM	Retina India	none				
Iran	CM	Iran RP Center	2011	4'500	3300	0	1200
Spain Fundaçion	CM	Fundación Retina España	2011	2540	2500	30	10
Taiwan	CM	Retinitis Pigmentosa Foundation Association in Taiwan	2010	312	270	12	30
Argentina	IG	Fundación Argentina de Retinosis Pigmentaria	none				

Country	Status	name of organisation 1	last update	Total members	Patients	Donors	Others
Hungary	AM	"For Our Sight" Foundation	2007	2800	1500	1000	0
China	IG	RP Committee	none		600000	0	0
Chile	IG	FUNDALURP	none				
Cyprus	IG	Pancyprian Organization of the Blind	none				
Denmark	IG		none				
Hungary	IG	Retina Hungary	2008	330	300	10	0
Israel	IG	NAMAG - Association of AMD patients in Israel	none				
Malaysia	IG		none				
Mexico	IG		none				
Netherlands	IG	NVBS / Retina Belangen	none				
Philippines	IG		none				
Rumania	IG	Pro Oculo Pro Viso FO ROMANIA	none				
Singapore	IG	Eye & Retina Surgeons	none				
Singapore	IG	Retinitis Pigmentosa Society (Singapore) / RPSS	2007	388	334	0	54
South Korea	IG	Korean Retinitis Pigmentosa Society (KRPS)	none				

Appendix 2 to president' s report 2010-2012

Travel activities of RI president

Location	Task	Start	End	Days
Stresa	MC Meeting	28.06.2010	28.06.2010	1.0
Montreal	RD meeting	11.07.2010	17.07.2010	7.0
Paris	Allergan patient organisation meeting	02.09.2010	02.09.2010	1.0
Brussels	efgcp Partnership in clinical trials	17.09.2010	17.09.2010	1.0
Aachen	Pro Retina meeting	14.10.2010	16.10.2010	3.0
Dublin	Patients and science meeting	11.11.2010	13.11.2010	3.0
Brussels	Eposi Workshop	29.11.2010	30.11.2010	2.0
Geneva	Symposium University of Geneva	02.12.2010	03.12.2010	1.0
Taipei (Taiwan)	Sight visit in conjunction RI conference 2016	10.03.2011	16.03.2011	6.0
Dusseldorf	Programme committee RI 2012	22.03.2011	23.03.2011	2.0
Brussels	Eposi Workshop	29.03.2011	30.03.2011	2.0
Geneva	Dia Conference	30.03.2011	02.04.2011	3.0
Boston Ft.	Novartis Havard	27.04.2011	29.04.2011	3.0
Lauderdale	ARVO	29.04.2011	06.05.2011	7.0
London	Eurovisionnet Meeting	27.05.2011	27.04.2011	1.0
Brussels	Eurovisionnet Hearing at EC	21.06.2011	23.06.2011	2.0
Baltimore	MC meeting and visions conference	23.06.2011	27.06.2011	3.5
Baltimore	Lecture John Hopkins, Wilmer Eye Institute	24.06.2011	24.06.2011	0.5
Karlsruhe	Meeting with Pro Retina Germany to prepare conference	24.08.2011	24.08.2011	1.0
New Delhi	Retina Aware	17.09.2011	30.09.2011	4.0
Berlin	Preparation RI conference	01.10.2011	01.10.2011	1.0
Santiago de Chile	Patient conference	26.10.2011	31.10.2011	5.0
Dublin	Research and patient conference	10.11.2011	13.11.2011	3.0
Neapel	Patient symposium	01.12.2011	03.12.2011	3.0
Brussels Ft.	Irish Patient organistion Engage	21.03.2012	21.03.2012	1.0
Lauderdale	ARVO	03.04.2012	12.04.2012	9.0
Total				76.0