



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

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Retina International General Assembly 2016 - Taipei, Taiwan

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APPENDIX 03-1

3.1 President's Report and MC Reports 2014-2016

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1. Introduction

This report covers the activities of Retina International from July 2014 to June 2016. The General Assembly (GA) in France elected the following officers to the Management Committee (MC):

Christina Fasser (President)
 Fraser Alexander (New Zealand)
 Claudette Medefindt (South Africa)
 Abdullah M. Yusuf (Pakistan)
 Caisa Ramshage (Sweden)
 Kin Ping Tsang (Hong Kong)

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
- Establishment of the Retina International office in Dublin

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 2014 in Paris.

3. Term of office report 2014 - 2016

3.1 Introduction

At its first face-to-face meeting, held prior to the GA in Paris, 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 include more of our member organisations thereby making the best use of their knowledge and experience.

Unfortunately our call for volunteers met with a 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 2014 in Paris.

The MC held a mid-term meeting in November 2015 in Dublin. The meeting was organised to plan for the set-up of the RI office, to oversee the on going work of the RI President's office and to allow for participation in a workshop on patient reported outcomes in clinical trials. This meeting was also attended by Kristin Halldór Einarsson from Iceland, who declared interest to be nominated for the MC and wishes to become more involved in Retina International's activities.

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 build relationships with new and developing members in order to provide them with the advice and support needed to establish a strong organisation of patients with retinal degenerative diseases. At the GA 2016, we will have the pleasure to welcome at least two (4) new organisations into the RI family. However, with sadness we will also have to accept to downgrade some of the member organisations to the Interested Group level, since they were unable to fulfil their financial obligations.

The financial crisis has hit a number of them enormously. Iran still has no way to export funds because of the political restrictions, the same applies to Argentina. Greece faces very severe restrictions on export of funds; however, to their great credit they have paid part of their fees.

With sadness we see FFB Canada leaving Retina international, because they do not want to provide funds outside of Canada.

3.2.2 Membership Sub-Committee report

Member: Claudette Medefindt

1 MEMBERSHIP APPLICATIONS

Applications for membership have been received from:

Association Retina Maroc

Their documents are in order and the MC recommends that the organisation under the leadership of Mahomed Bentayaa be accepted as a Candidate member.

Fundacion Retinitis Pigmentosa de Puerto Rico

This organisation under the leadership of Santa Nieves has applied for membership. All the documentation is in order and the MC recommends that they be accepted as a Candidate member.

Macula Retina – Spain

This organisation under the leadership of Juan Manuel Cabañas has the name Macula but they also have members with RP. Their application is in order and the MC recommends that they be accepted as a candidate member.

Retina Cyprus

They are ready to apply for Candidate membership but will only have their first year end financial reports ready in October this year. The MC recommends that they be accepted provisionally as a Candidate member with the provision that all relevant and accurate documents be provided before year end 2016.

Lirot - Lirot - The Israeli Research Association for Eye Health and Blindness Prevention

As they are not a patient based organisation their application is to be an Associate member.

The application is in order and the MC recommends that this application be accepted.

No replies received from

- China Association of the Blind,
- Associazione Pro Retinopatici e Ippovedenti (Italy)

New application forms have been sent to

- Search for Vision – USA
- Curing Retinal Blindness - USA
- Usher Syndrome Coalition - USA

Change of Name

The MC recommends that Retina Netherlands be officially changed to Oogvereniging Retina.

Resignations

The Foundation Fighting Blindness Canada

Canada has emailed RI saying that “We will continue to support Retina International but cannot commit funds at this time.”

It is with regret that the MC recommends that Canada be downgraded.

Interested organisations and groups

Emails are sent to individuals or groups to encourage them to become more active in their community and where possible to develop towards a more formal group.

Mexico

They are listed as an interested group, two individuals are listed and have been encouraged to join forces and to apply for membership.

Uganda

Emails are exchanged with Uganda on a regular basis. No formal application for membership has been received.

Emails replies to Retina International

Decreasing number of emails from individuals is being sent to me via Retina International. We hope that this means that patients are now using reliable internet sources for information.

Emails were sent to 13 patients (down from 25 in previous 2 year period) from 10 countries (17 previous reports):

Algeria, Australia, India, Malawi, Mauritius, Nigeria, Pakistan, Sudan, Tanzania and Zimbabwe.

Membership Status (Prior to this meeting)

Full members: 24 (down from 26 in 2014)

Candidate Members: 4 (down from 5 in 2014)

Interested groups: 20 (up from 11 in 2014)

Associate members: 1

The total is 49 (up from 42 in 2014)

Decisions to be made on Membership Status

Members have declined to pay fees or have requested a suspension of fees for economic purposes:

Argentina (CM), Canada (FM) and Greece (FM).

3.2.3 Governance report

The main issue relating to governance is the establishment of a RI office.

In September 2015 Avril Daly was appointed as new CEO and she started her work in January 2016. Her main objective for the first six months was to find the funds to sustain the RI office from July 2016 onwards.

The activities of the new CEO, the strategic objectives and work plan 2016-2018 as well as the relative budget will be the object of two separate reports.

The GA 2012 asked to change the accounting system to accrued accounting. The president's office together with a chartered accountant changed the accounting system in 2013. The new balance sheet is presented in that new way. In 2015 the Swiss law changed slightly and the system has been adjusted to this new regulations and a status report has been added.

3.3 Research

The main task of the research committee is to work in close cooperation with Professors Gerald G. Chader, Joe Hollyfield and Eberhard Zrenner to organise the RI SMAB meetings at the ARVO meetings in Denver in 2015 and Seattle in 2016. The agenda has to be developed, the speakers invited and the meeting location and logistics organised. We are proud to report that this meeting has developed such a high reputation that invitations are highly sought and attendance is limited.

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.

Whenever possible, the president represents and advocates for the needs of patients with retinal degenerative diseases. A comprehensive list of the speaker's engagement on behalf Retina International is added to this report. In September 2015 Retina International organised a symposium within the EURETINA Conference 2015 for the first time, the event in Nice, France was very well attended and we will once again organise a symposium at the EURETINA Conference 2016 in Copenhagen, Denmark. During the EURETINA Conference 2015 we laid the foundation for the organisation of the European Reference Network (ERN) for Rare Eye Disease that will be submitted to the EU in June 2016. A small organising committee met in Zurich on February 26, 2016 and a kick-off meeting with over 40 researchers and clinicians took place in Strasbourg on April 18th, 2016. Should this application be successful, we will have a network of reference centres throughout Europe with links to all important centres world-wide improving markedly the access to treatments and care of patients with rare retinal degenerative diseases.

Retina International was asked to be part of the scientific board of several EU funded projects: Treatamd Drugsford, nanomed, AMD Risk etc... The projects aim to bring basic research to the bed-side, and to bring drug development to clinical trial stage, respectively. Emphasis is also given to the need to develop criteria for early detection and to improve access to genotyping.

Retina international is also involved in a major EU application aiming to improve diagnosis and genotyping of rare inherited retinal degenerations. If this application is successful, RI can employ a communications professional for this project.

The annex on travel activities gives a detailed overview of the different activities.

3.4 Communication and Marketing

Member: Fraser Alexander

My 2014-2016 work in marketing and communications was largely focussed on providing comment and analysis in support of the re-launch of the Retina International website. With the appointment of the CEO role, a significant financial resource and participation across the entire MC, I am delighted to report that this project has been a major success. In Taiwan Avril will present an accessible, responsive and flexible site that clearly communicates who we are, our Mission Vision and Values and why we exist. Carrying through my work in recent years with articulating the benefits of partnering with RI, the site will provide accessible information about our core functions. I encourage regular visits as the site will support our mission by:

- supporting our core functions in promoting and stimulating research into retinal dystrophies
- engaging with the global scientific community
- promoting the services provided by National Foundations and fostering mutual support
- promoting awareness globally through the maintenance of a high degree of international contact and exchange of literature
- promoting the establishment of societies of people with retinal degenerations in countries where such societies do not already exist.

The role of chairing the Local Organising committee for the 2018 Retina International World Congress in Auckland and duties as president of Retina New Zealand has impacted on available time but marketing Retina International across the Aisa-pacific region will be a natural by-product of hosting RIWC 2018. Promoting Retina International to traditional non-participant regions such as the pacific islands and South East Asia has commenced and we hope to add 3-5 new members by the time Auckland concludes in February 2018.

3.4.1 World Retina Day 2014 and 2015

Two press releases have been issued and distributed among our membership.

3.4.2 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.

In 2015 the need of a new web design was obvious: The site needs technical adaptations to be also accessible on iPad and Smart phones. RI received a grant of 23'000 for a re-launch of the website. The new website

should officially be launched at the Retina International Conference 2016 in Taipei.

3.5 Retina International Conferences

3.5.1 Paris (France) 2014

The Retina International Conference was held successfully in July 2014 in Paris (France). The conference was excellently organised and a great success with 1000 participants from more than 50 countries. The format of the conference was unique for France and the contact between patients and scientists was extremely appreciated.

3.5.2 Taipei (Taiwan) 2016

The GA 2012 granted the hosting of the conference in 2016 to Retina Taipei and Retina Hong Kong and it will be held in Taipei (Taiwan). With good collaboration between the two organizers. The program is formulated with diverse topics which are of interest to patients and experts in retinal degenerations alike. Updates on emerging therapies and clinical trials will be shared with participants at the Conference. Financial support is provided through a number of industry partners and local government departments. So far we have a significant registration of attendees and we are confident of an excellent turnout in Taipei this July.

3.5.3 Auckland (New Zealand) 2018

Established in October 2015, our event management timeline has been important in ensuring that steady progress can be made by the local organising committee. We are fortunate to have signed an event team who produces a large number of similar events each year- Event Services, University of Auckland . Our focus in recent months has been on securing the vital finances we need from a number of sources - sponsorships, donations, exhibitors and statutory bodies. We expect to have secured 60% of our funding budget by the end of 2016. Our plan is to complete communications and marketing tasks so that we can go live with our website prior to the upcoming Taiwan World congress in July 2016. We have made good progress with web design and copy, ensuring accessibility, writing key messages and designing a media and communications plan. The programme design/speakers shortlist process has begun with a view to sending invitations in September 2016. Most of the Education and Social programme will be held on campus at the University of Auckland in the central business district and we will be working hard to ensure accessibility is maximised by working closely with blindness rehabilitation professionals and student volunteers. Critical to our success will be our ability to attract registrations from outside Auckland and outside New Zealand. Our communications plan will include an exhaustive promotions campaign aimed at patient groups, professional

organisations, biomedical research institutions, Universities, ophthalmology and optometry practices, rehabilitation and equipment providers, health and disability administrators and other aligned groups right across the Australasia and Asia-pacific region. The congress social programme will offer high-quality experiences and unique opportunities to immerse delegates in maori and Polynesian culture whilst providing a historical perspective of the city and the country. Pre-congress and post congress touring information will be delivered in accessible electronic formats and in person at the congress to ensure delegates take full advantage of endless adventures from island retreats and wine tours to bunjy jumping and sailing. Our modern city centre is surrounded by sparkling harbours, native rainforest, beautiful beaches and scenic wine regions, offering a huge range of activities.

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. After two conferences in Asia and New Zealand, we are happy that two organisations are bidding for the conference 2020: Fighting Blindness Ireland and Retina Iceland.

3.6 Youth

Member: Caisa Ramshagen

During the Retina International conference in Paris there was a parallel youth program with different activities such as a picnic and tours. The last days of the youth program was integrated with the ordinary Retina International Conference. A special lecture was held for the youth by prof. Gerald Chader. This lecture was very much appreciated by the youths as it explained the science from a basic level. For many in the youth group it is the first time they will attend a scientific lecture regarding retinal degeneration and many are not native English speakers. The youth program was much appreciated by participants who came from New Zealand, Netherlands, Norway and Sweden.

The programme was arranged by Zane Bartlett from New Zealand with assistance from Caisa Ramshagen. It was difficult to plan the youth meeting since none of the organisers were present in Paris during the planning time and had no local knowledge.

In the future we wish to include the youth meeting in the planning of the Retina International conference and ask that the member organisations work proactively in engaging youths in their own organisation and also seek funding in order to be able to send at least one youth delegate to the RI conference.

There will also be a youth programme at the Retina International conference in Taiwan.

3.7 Retina International Operations

3.7.1 Funding and accounts

The budget of Retina International includes three major items:

- Basic running costs (phone, mailing, stationery, travel costs)
- Costs of assistants
- The Retina International website

The MC and the president endeavoured to be cautious in its spending and stayed within the budget, allowing for an increase in the capital, despite the fact that we are still faced with down-payment plans and non-payment of fees. The president is concerned that new members are not joining due to inability to pay fees, or that after a short period of membership; organisations stop paying and have their membership downgraded. It seems that financial considerations are hindering Retina International from moving forward.

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 especially in the form of travel grants in order to increase the visibility of RI. Furthermore thanks to two major grants from Novartis the website can be improved and a workshop and White Paper on patient reported outcomes in clinical trials can be carried out in 2016.

The net capital of RI is healthy at present. However, we are heavily engaged in the RI office and trying to cut costs and make savings wherever possible. In order not to increase the membership fee, we will not continue the scientific newsletter. This part of the website will be re-designed should there be additional funds available.

The Swiss regulations have been changed in 2015 and therefore we had to make slight adjustments and new a status report has to be provided.

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 mean 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, 50% support is necessary instead of 30%. The installation of the RI office also increases temporarily the time the president has to dedicate to RI affairs.

Members could easily help to save assistant's time and funds by paying fees in time and by sending their documentation and address changes without prior reminder.

3.7.3 Retina International Office, Dublin

The MC has established a work plan for the first six months, a job description and an announcement for a CEO. The job of a CEO has been published and the MC has hired Avril Daly as its first CEO. FB Ireland is hosting the Retina International Secretariat. In order to guarantee a smooth transition, Retina International agreed to wait so long until FB Ireland has hired its own new CEO. This resulted into the beginning of the Retina International Secretariat effectively in January 2016. The main objective for the first six months of the CEO was to establish contacts and a fundraising strategy to secure funding for the period 2016 - 2018. A special report will be presented to the GA by the CEO.

3.7.4 Travel activities of the president

Participation in meetings and conferences increases the visibility of Retina International. During the term of office the president committed to the following travel activities:

Travels abroad of 103.5 days

The most important travel commitments were:

- ARVO 2015
- ARVO 2016
- Travel to Tübingen and Hamburg to honour Prof. Eberhard Zrenner and Prof. A. Gal

A list is added to this report. The president is making sure that as much as possible of the travel costs are funded externally.

3.8 Support of research applications

MC members were actively involved in preparing several applications for research support by the European Union. This was 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 moving things forward.

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.

A major effort was made by the SMAB and the RI presidency to bring clinicians together to apply for the European Reference Centre network initiative (ERN). Deadline for the grant application is 21st of June and at the time of writing this report we can say that over 40 health providers throughout Europe are putting together a consortium. An ERN for Rare Eye Disease will improve the care of all patients with rare eye diseases and facilitate the participation in clinical trials.

3.9 Retina Europe

Report by Rainald von Gizycki and Michael Laengsfeld

Retina Europe, a section of Retina International, has been active as (partly informal) member organization within the following European organizations:

- European Disability Forum (EDF)
- European Patient Forum (EPF)
- European Organization for Rare Diseases (Eurordis)
- European Medical Association (EMA)

Meetings

Retina Europe was represented by Christina Fasser, Avril Daly, Rainald von Gizycki and Michael Längsfeld.

EDF: In 2015 and 2016 we participated in the General Assembly in Zagreb and in Dublin.

EPF: Participation in the General Assembly for 2015 and 2016, participation in a leadership forum 2016 and as well as in a conference for European patient rights in Brussels.

Eurordis: Participation in the General Assembly 2015 and in research-related workshops in Madrid.
Summer school and conference on patient-related outcomes in Barcelona.
Meeting of Council of European Federations (CEF) in Paris.
European Patient Advocacy Groups (EPAG).
European Reference Networks (ERN).
Eurordis also provides the Rare Connect platform for Rare Diseases for choroideremia patients worldwide, founded and moderated by Michael Längsfeld.

EMA: Participation in scientific advice working parties in 2015. Committee and planning of activities together with Eurordis concerning protocol assistance, gene therapy for CHM, cooperation with rare disease patient organizations etc.

We believe that the following improvement of our activities is recommendable:

- More information exchange among RE representatives prior to and after the meetings
- Clearer definition of roles of RE representatives and participants from national Retina organizations

The increase in these activities is due to better understanding of all European regulatory institutions that patient involvement is a basic requirement for more patient-oriented medical services and patient centered research at all levels.

3.10 AMD Alliance

In July 1999, Retina International became aware of 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. As a consequence AMD Alliance underwent a re-organisation and is about to reform its structure and objectives. 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.

However, in 2015 AMD Alliance was facing problems in financing its activities and in early 2016 the present chair, Mark Ackermann, had to call a halt of activities. It was assured that there are no financial debts.

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. This took place in Denver 2015 and in Seattle 2016. 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 which is successfully developing 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 budgets and rules. Although these provide the basis for good governance, they should not become the focus point of action. The General Assembly 2012 opened the way for a professional office and CEO for Retina International thus having a person available full time to attend to all the daily challenges. The GA 2014 allocated funds for six months running costs. In January the new CEO, Avril Daly, has started her job and is seeking the funds to assure sustainability of the project. However, I wish not to hide, this is an enormous task. The president and the CEO would be greatly thankful; if somebody who has good contacts would help with the fundraising.

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 we need 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 we cannot 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 225 genes are identified that cause inherited retinal degenerative diseases covering probably slightly more than 70 % 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.
- Avoid segmentation among patient organisations: A number of clinical trials are starting up for specific forms of retinal degenerative diseases. It is understandable that patient groups tend to split off in the hope of accelerating the development for their own disease.

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 on 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.
- Improve co-operation with the organisations of rare diseases and take advantage of their new platforms such as Rare Connect.

5. Acknowledgements

I would like to express my sincere thanks to the members of the Management Committee and our CEO Avril Daly 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 Fighting Blindness, Ireland and especially to Avril Daly, the new CEO Kevin Whelan and Anna Moran who took on the difficult task to give support with the development of all the papers for the GA 2016.

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 other funding agencies and congratulate them on their success.

I would also like to acknowledge the generous financial support of Novartis for the development of the new website and the PRO Whitebook as well as the financial start up assistance by Retina Implant AG and Okuvision GmbH.

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.

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, 2016

Appendix 1 to president's report 2014-2016

Member Organisations

Country	Status	name of organisation
Australia	FM	Retina Australia
Belgium	FM	Retina Pigmentosa ASBL
Brazil	FM	Retina Brazil
Canada	FM	The Foundation Fighting Blindness - Canada
Finland	FM	Retina Finland
France	FM	Retina France
Germany	FM	Pro Retina Deutschland e.V.
Greece	FM	Hellenic Retina Society (M.E.A.)
Hong Kong	FM	Retina Hong Kong
Iceland	FM	Retina Iceland
Ireland	FM	Fighting Blindness
Italy	FM	Retina Italia (Onlus)
Japan	FM	JRPS
Netherlands	FM	Oogvereniging Nederland
New Zealand	FM	Retina New Zealand Inc.
Norway	FM	Retinitis Pigmentosa Foreningen i Norge
Pakistan	FM	Pakistan Foundation Fighting Blindness
South Africa	FM	Retina South Africa
Spain	FM	FARPE
Sweden	FM	Svenska RP-Föreningen
Switzerland	FM	Retina Suisse
Taiwan	FM	Retinitis Pigmentosa Foundation Association in Taiwan
UK	FM	RP Fighting Blindness
USA	FM	The Foundation Fighting Blindness Inc.
Argentina	CM	Fundación Argentina de Retinosis Pigmentaria
Argentina	CM	Startgardt APNES

Chile	CM	FUNDALURP
Spain Fundación	CM	Fundación Retina España
Hungary	AM	"For Our Sight" Foundation
China	IG	RP Committee - China Association of the Blind
Cyprus	IG	Retina Cyprus
Hungary	IG	Retina Hungary
India	IG	Retina India
Iran	IG	Iran RP Center
Israel	IG	NAMAG - Association of AMD patients in Israel
Israel	IG	Lirof Association
Malaysia	IG	Teoh Beng Hian
Maroc	IG	Association Retina Maroc
Mexico	IG	Patricia Eugenia Zubirán de Aguilera
Philippines	IG	
Poland	IG	Retina AMD Polska
Portugal	IG	Associação de Retinopatia de Portugal (ARP)
Puertorico	IG	FUNDACION RETINITIS PIGMENTOSA DE P.R
Saudi Arabia	IG	Hatim Abuzinadah
Singapore	IG	Eye & Retina Surgeons
Singapore	IG	Retinitis Pigmentosa Society (Singapore) / RPSS
South Korea	IG	Korean Retinitis Pigmentosa Society (KRPS)
Spain	IG	Asociacion Macula-Retina
Uganda	IG	Retina Uganda

Appendix 2 to president' s report 2014-2016

Travel activities of RI president during the term of reporting

Location	Task	From	To	Days
Bremen	Drugsford Meeting	08.09.2014	12.09.2014	4.0
Reykjavik island	members meeting	08.10.2014	11.10.2014	4.0
Zurich airport	Novartis Global Meeting	22.10.2014	23.10.2014	2.0
Dublin	Science Meeting	06.11.2014	08.11.2014	3.0
Oxford	EURETINA Winter meeting	23.01.2015	23.01.2015	1.5
Zurich	Audit	10.02.2015	10.02.2015	0.5
London	EMA HTA	22.02.2015	23.02.2015	2.0
Tuebingen	Drugsford Meeting	03.03.2015	05.03.2015	3.0
London	EMA Drugsford Orphan Drug	17.03.2015	17.03.2015	1.0
Zurich airport	Novartis Retina Forum	22.03.2015	23.03.2015	1.0
Zurich	Velux workshop	10.04.2015	10.04.2015	1.0
Zurich airport	Novartis Retina Forum	15.04.2015	16.04.2015	1.5
Denver	ARVO	01.05.2015	08.05.2015	8.0
Madrid	Eurordis GA and CEF	27.05.2015	30.05.2015	3.0
Barcelona	Eurordis Summer school	31.05.2015	06.06.2015	6.0
Zurich	Novartis Global Franchise Meeting	24.06.2015	24.06.2015	1.0
Basel	Novartis Global patient forum	30.06.2015	01.07.2015	1.0
Hamburg	Symposium to honour prof. Gal, talk EURETINA, symposium and ERN preparation	09.09.2015	10.09.2015	1.5
Nice		17.09.2015	20.09.2015	3.0
Stockholm	ALCONe Advisory board on clinical trial	23.09.2015	26.09.2015	2.5
Berlin	DOG, talk for special symposium	01.10.2015	02.10.2015	2.0
Tuebingen	Symposium in honour of Prof. Zrenner	15.10.2015	16.10.2015	1.5
Cyprus	inauguration Retina Cyprus	18.10.2015	20.10.2015	3.0
London	EBU, talk about artificial vision	26.10.2015	26.10.2015	1.0
Paris Symposium Sahel	Eurordis ERN	28.10.2015	29.10.2015	2.0
Dublin	Science meeting and MC	04.11.2015	08.11.2015	4.0
Paris	Retina France member meeting	20.11.2015	21.11.2015	1.5
Amsterdam	kick-off meeting nanomed	24.11.2015	25.11.2015	1.5
Dublin	Introduction CEO	03.01.2016	06.01.2016	3.5
Basel	Meeting with Novartis, S. Jjekgik	11.01.2016	11.1.2016	1.0
Brussels	EPF Leadership Meeting	03.02.2016	04.02.2016	1.5
Zurich airport	Novartis Steering Group patient Meeting October	10.02.2016	10.2.2016	0.5
Zurich	RI audit	12.02.2016	12.2.2016	0.5
Brussels	Eurordis HTA Workshop and Gala	23.02.2016	25.02.2016	2.5
Brussels	EPF AGM	21.03.2016	24.02.2016	3.5
Strasbourg	kick-off meeting ERN	17.04.2016	18.4.2016	1.5
Seattle	ARVO	30.04.2016	07.05.2016	8.0
Paris	Symposium José Sahel	06.06.2016	07.06.2016	2.0
Amsterdam	Members meeting	10.06.2016	11.06.2016	2.0
Brussels	Health policy workshop on GA	21.06.2016	22.06.2016	2.0
Taipei	RI conference	05.07.2016	12.07.2016	8.0
				103.5

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