



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

T

Retina International General Assembly 2018 - Auckland, New Zealand

Thursday, February 8th, 2018

Location: University of Auckland Business School

Owen G Glenn Building, 12 Grafton Road, Auckland, 1010

Room: Decima Glenn Room, Level 3

Start: 09.00 a.m. end: 05.00 p.m.

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1. Introduction

This report covers the activities of Retina International from July 2016 to January 2018. The General Assembly (GA) in Taipei elected the following officers to the Management Committee (MC):

Christina Fasser (President)
Fraser Alexander (New Zealand)
Kristin Halldor Einarsson (Iceland)
Michael Laengsfeld (Germany)
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, the CEO 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 retina International activities should be viewed in the light of this objective.

Major areas of focus 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 and communications
- Establishment and sustainability of the Retina International office in Dublin

The aim of the sub-committees is 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 2016 in Taipei.

3. Term of office report July 2016 - January 2018

3.1 Introduction

At its first face-to-face meeting, held after to the GA in Taipei, 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 member organisations to participate in the development of our organisation by utilising their considerable knowledge and experience.

Unfortunately, our call for volunteers was 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. However, there was involvement by members in the development of capacity building projects with positive outcomes and we hope this can be expanded upon in the period 2018-2020.

This report is structured along the work plan accepted by the GA 2016 in Taipei.

The MC held a mid-term meeting in September 2017 in Barcelona in connection with EU Retina, which is a major conference for medical and scientific experts as well as industry working in the retina space. While it is a European event EU Retina now attracts a global audience and was a good opportunity for the MC to meet with the industry representatives who collaborate with and support Retina International but also the scientists and clinicians the organisation works with. The inaugural Retina International Meeting of Partners (RINP) took place the day before the conference on September 6th and allowed for participation in a symposium organised by Retina International during EU Retina.

At the MC meeting the group reviewed the objectives of the organisation in particular work plan and sustainability of the RI office, the on-going work of the RI President's office and preparation for the RINP and the General Assembly.

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, the president and CEO 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 2018, we will have the pleasure to welcome back at least two earlier 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. Last time we reported that with sadness FFB Canada were leaving Retina international. However, we are happy to report that FFB Canada will re-apply to become a full member of the organisation in 2018.

3.2.2 Membership Sub-Committee report

Member: Claudette Medefindt

The MC evaluated the membership structure and decided that there was a need to adapt it.

The membership sub-committee proposes that the constitution of Retina International be amended to include an extra category of membership i.e. A B C category membership.

Section 4.2 of the constitution shall be amended as below.

Membership

- 4.1.1 The membership of Retina International is open to societies of people with a retinal dystrophy and organizations with a specific interest in retinal dystrophies.
- 4.1.2 In the instance of more than one full member in a country, the respective boards of the individual organisations, and their scientific and medical advisory boards (SMABs), are encouraged to meet at least once a year to avoid duplication of effort.

4.1.3 If such meetings take place, as described in 4.1.2, a report should be sent to the Retina International president.

4.2 Membership Classification

Five (four) classes of Retina International membership exist:

4.2.1 FULL MEMBERSHIP

In order to be a full member of Retina International, a society must show that:

- 4.2.1.1 it is a charity duly registered as such under its national laws (see note to 1. Definition), and has a constitution or is a sub-group of a larger organisation, such as a society for the blind, that has a constitution
- 4.2.1.2 its purposes coincide with Retina International's objectives,
- 4.2.1.3 it is a society for people with Retinal Dystrophies such as Retinitis Pigmentosa (RP), Usher Syndrome, Macular Degeneration and other allied retinal dystrophies and their families and friends with sound scientific and medical support,
- 4.2.1.4 it may be a standalone organization or a sub-group of an organization for the blind, but in the latter case must give proof of independent activities and accept all people with retinal degenerative diseases irrespective of their stage of visual impairment. Membership should also be extended to parents of minor children with retinal conditions
- 4.2.1.5 a medical and scientific advisory board or committee has been constituted and approved by the Retina International SMAB,
- 4.2.1.6 up-to-date audited accounts have been provided to the RI Management Committee.

4.3 CANDIDATE MEMBER

A candidate member is a society which has stated an intention to apply for full membership in the future or which has already applied for full membership, but either:

- 4.3.1 In the opinion of the GA is not yet in a position to meet all the criteria for full membership, or,
- 4.3.2 Is a first-time applicant for Retina International membership which apparently meets all the criteria for full membership, in which case it must serve as a candidate member for two years prior to applying for full membership.

4.4 INTERESTED ORGANIZATION

Interested organizations include retinal dystrophy societies that are in the early stages of becoming organised and established organizations that would never apply for full membership in their own right, for example, blindness organizations that do not have separate retinal dystrophy sub-groups.

To accomplish that people with a Retinal Dystrophy can find solace, hope and a future it is necessary to broaden the influence of Retina International. Only helping, advising and binding new groups to Retina International can do this. Therefore, the first step is interest.

Interested organizations are those:

- 4.4.1 which are not yet in a position to become a candidate member or will never qualify to become a candidate member,
- 4.4.2 which need all the support to acquire enough strength or potential to reach the next phase as candidate member,
- 4.4.3 which will be on the Retina International mailing list and will be assigned a member of the MC as primary contact.

4.5 ASSOCIATED ORGANIZATION

Associated organizations include companies, scientific institutes and funding organizations that will never be in a position to fulfil the requirements of the other membership categories of Retina International. An associated organization promotes, funds or actually conducts research into retinal dystrophies and is not enlisted to Retina International through other channels.

- 4.5.1 Associated organizations will not be present at the General Assembly unless by special invitation of the MC,
- 4.5.2 Associated organizations will have no voting rights,
- 4.5.3 Associated organizations can have a seat in the SMAB where they can help influence the course of research,
- 4.5.4 Applications to become associated organizations must be approved or rejected at the next General Assembly,
- 4.5.5 Associated organizations will pay fees.

- 4.6 B Category membership may be extended to organisations and patient groups who are not in a position to comply with all the requirements of full membership but wish to contribute to the work and objectives of Retina International. These organisations will be invited as observers to the General Assembly but will not be

entitled to vote. The membership fees of each organisation will be determined by the finance sub- committee and will be directly proportional to the rights that they are accorded.

Membership rights at present are:

1. 2 members may attend the GA
2. They have one vote at the GA
3. Propose a member/s for the MC
4. Make representations to the GA
5. Attend the CE program
6. Apply to present at the CE
7. Have 2 delegates on the SMAB international
8. Invite delegates to attend the SMAB meeting
9. Use of RI logo
10. Details on website
11. Access to Scientific information
12. Attend the RI conference

| Membership cat | Rights | Payment |
|---|--|--|
| Full | Full | As present |
| Candidate | Observers at GA and CE then 4,5,10,11,12 | As present |
| Cat: B (Does not comply with all membership requirements) | To be determined by Membership committee in conjunction with finance sub committee | To be determined by Finance committee |
| Cat: Associate member | Attend CE as observers then 9 to 12 | To be determined by Finance committee (at present E 500) |
| Cat: Interested group | As above | Finance committee |

3.2.3 Governance report

The main issue in Governance was the different membership categories, that do not allow for organisations that do not accept parents as members in their full right. The GA 2018 will be presented with a respective proposal. Furthermore, we need to deal with the fact how to handle organisations that were full members and return after having left. A respective proposal is submitted to the GA 2018 (see also membership report). (Note from

3.3 Research

3.3.1 General activities

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 Seattle in 2016 and Baltimore in 2017. 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 CEO and the president represent and advocate 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.

As mentioned previously in September 2016 and September 2017 Retina International organised a symposium within the EU Retina Conference. this marks the continuation of a series of symposia dedicated to support of research, drug development, patient reported outcome measures and reimbursement.

Retina International was asked to be part of the scientific board of several EU funded projects: Treatamd ocuTher, nanomed, AMD Risk, medtech 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 was also involved in a major EU application aiming to improve diagnosis and genotyping of rare inherited retinal degenerations. If this application would have been successful, RI could employ a communications professional for this project. Despite two trials and a high ranking of the project it was denied funding. However, we are pleased to report that we have acquired funding elsewhere to finance a Science and Communications Officer to work on areas such as this starting early 2018.

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

3.3.2 Patient reported outcome measures

Patient reported outcome measures are becoming more important and need to be evaluated according to the stringent criteria of research. In 2015 RI started to bring the topic on the agenda of researchers and policy makers in organising a first meeting in Dublin. In 2017 in Washington in co-operation with FFB-USA we organised a meeting which was attended by more than 80 persons from academia and industry as well as by representatives of the regulatory bodies FDA and EMA. It was decided there to publish the outcome of the meeting in a paper and a first editorial meeting was organised by RI in Baltimore during ARVO 2017. The process of writing up the document is in progress; further discussions will take place in 2018 with publication planned for later that year.

3.3.3 ERN European Reference Network for Rare Eye Diseases

Retina international was strongly involved in the preparation of the application of the ERN Eye through its president and CEO. The application was successful and in March 2017 the ERN Eye was granted the status by the European Commission. The network comprises 29 Health Care Providers (HCP) in 13 countries. In early December 2017 a call will be published to accept new members from countries where no HCP is already part of the network. This concerns mainly Ireland, Spain, Sweden and Norway. This network will improve patient care and health innovation throughout Europe, should enable access to the best quality of treatment and support and stimulate new research. The ERN process will network globally which is critical for our organisation.

3.4 Communication and Marketing

Member: Fraser Alexander

In accordance with the GA 2016 directives, in early 2017 Fraser Alexander commenced work with the CEO on a "Communication and Marketing Strategy Overview and proposed an actions document". The Communications and Marketing Objectives of Retina International are to establish it as the leading organisation for supporting research in retinal degenerative diseases, advocating for access to care and treatment and in providing relevant up to date patient information. In the belief that a more professional approach requires better investment in communications platforms and a coordinated strategy for the dissemination of information, we proposed a list of 10 actions.

The Dublin office has made significant progress in a number of areas, many of which are currently being simultaneously incorporated into the communications and marketing plan for the 2018 RI World congress in Auckland. especially so in areas such as assembling a cohort of key opinion leaders, developing position statements on topics of particular interest and networks of site contributors. I plan to focus on individual actions that contribute to many of the 10, if elected, in the 2018-2020 MC term.

1. Develop and implement a process for the dissemination of the most up to date news, views and information through IT platforms, newsletters and mail outs.
2. Develop a process to regularly update the RI website for maximum impact and to attract regular visitors.
3. Develop a Social Media policy,
4. Through membership develop a cohort of contributors to provide information to the site including Wikis and Blogs.
5. Implement a simple process to respond in a timely fashion to personal enquiries.
6. Publish Retina International statements and press releases for use by member countries.
7. Develop a cohort of key opinion leaders drawn from the membership, SMAB and learned societies to comment on developments within the research and development space.
8. Design printed materials that highlight the work of RI and why it is of value to join as a member or to support us as a corporation or a foundation.

9. Develop and implement a house style to be used in all communications materials to ensure accessibility and brand identification
10. Develop position statements on topics of particular interest.

3.4.1 World Retina Day 2016 and 2017

On World Retina Day 2016 the new Retina International Website was launched. On World Retina Day 2017 a toolkit on Genetic Testing was launched. The theme for 2017 was the importance of equitable access to and reimbursement of genetic testing services. Two press releases were issued and distributed among our membership. Consideration needs to be given to the fact that World Retina Day does not take place on the same day for all groups and so therefore cannot be called a 'World' day officially. RI will survey its members to gain its perspective on an approach to the WHO to designate and agreed date that is aligned to other stakeholder groups such as learned societies in the retina space.

3.4.2 Retina International Website

The website of Retina International was relaunched on World Retina Day September 24th 2016; member data is updated as and when it is supplied and the news and events pages are kept up to date with developments in research and policy. A Retina International YouTube channel has been set up along with a Facebook and twitter account. Traffic has increased in particular to the disease specific pages. Dara Creative are supplying a full report.

3.4.3 Genetic tool kit

SPARK Therapeutics funded with an unrestricted educational grant the development of an online toolkit on genetic testing for Inherited Retinal Diseases that was launched on World Retina Day, September 30th 2017. The toolkit is entitled RED Alert playing on the term Rare Eye Disease and taking ownership of this term for RI. The Toolkit consists of text describing the fundamentals of genetics, the evolution of testing services, the types of tests available and where they can be accessed. There is also a section on the risk and the benefit the important issues to be considered and the importance of genetic counselling services. The final section details the way in which we can work together to advocate for better access to testing and services. The toolkit has followed best practice and each text section is kept short and digestible and each section contains an explanatory accompanying video clip in the hope that these will be of benefit to those

who are vision impaired. A survey of patients and member organisation has allowed us to understand the need of our community and tailor the toolkit to address their requirements.

3.4.4 AMD tool kit

Hoffman LA Roche provided an unrestricted education grant to fund the development of an accessible, state of the art toolkit on AMD which was launched on November 27th 2017. The toolkit addresses the importance of improving screening processes globally to enable early diagnosis of AMD leading to prompt access to appropriate treatment. The toolkit clearly defines the early, intermediary and late stages of AMD and includes specific information on Geographic Atrophy (GA) and neovascular AMD. The toolkit includes detailed information on the reality of living with these life changing conditions and highlights the urgent need for greater understanding and support. It is designed for a wide and varied audience of stakeholders including the general public, at risk groups, patients and those who care for them, medical professionals and policy makers. Vicky McGrath was hired to facilitate the project with the RI Team and a coalition of global patient groups, scientific writers and a dedicated SMAB. The next step is to translate elements of the toolkit into six languages.

3.5 Retina International Conferences

3.5.1 Taipei (Taiwan) 2016

The Retina International Conference was held successfully in July 2016 in Taipei (Taiwan). 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 Taiwan and the contact between patients and scientists was extremely appreciated.

The organisers are to be complemented on their excellent organisational skills in adapting the conference schedule to the typhoon-imposed last minutes changes and re-scheduling.

3.5.2 Auckland (New Zealand) 2018

The GA 2014 granted the hosting of the conference in 2018 to Retina New Zealand and the conference will be held in Auckland.

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 Auckland this coming February 2018.

3.5.3 Reykjavík (Iceland) 2020

Report from Kristin Halldor Einarsson:

- Agreement is in place with the Icelandic Ophthalmology Association on common dates and venue for the Nordic Ophthalmology Congress in 2020 (NOK 2020) and Retina International World Congress in 2020 (RIWC 2020)
Dates: 03.06 – 07.06.2020.
Venue: Harpa – Concert and Conference hall. Reykjavík
- Agreement is in place with professional congress and event planner: CP Reykjavík – Conference Event Incentive.
CP Reykjavík will be servicing both NOK 2020 and RIWC 2020.
- Local organizing committee has been appointed and has started to work.
- The Scientific committee has been appointed, members are:
 - Chair: Prof. Ragnheiður Bragadóttir University of Oslo
Department of Ophthalmology.
 - Prof. Einar Stefánsson MD, PHD Department of Ophthalmology
National Hospital Reykjavik, University of Iceland
 - Prof. Jón Jóhannes Jónsson Chair of Department of Genetics
and Molecular Medicine at Landspítali University Hospital
 - Ms. Sigríður Masdóttir, head ophthalmologist at the Institution for
the blind in Iceland.
 - Mr. Sveinn Hákon Harðarson Assistance professor in
ophthalmology at the University of Iceland.
 - Prof. Thor Eysteinnsson Professor of neurophysiology at the
University of Iceland.

- Promotional material for RIWC 2020 to distribute on RIWC 2018 is ready.
- RIWC 2020 website will be launched at RIWC 2018

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. We are happy to announce that Fighting Blindness Ireland was not discouraged and will be bidding for the conference 2022.

3.6 Youth

Member: Caisa Ramshage

From the Management Committee we would like to stress the importance of engaging the youths of our member organisations. Even if we all would like to eradicate all retinal diseases it will take time and we need to find the right persons to take over the assignments in our organisations.

In Taiwan during the Retina International conference there was a parallel youth program which included both social parts such as National Palace Museum and Taipei zoo, but also a scientific programme by professor Elise Heon from Canada. The youths enjoyed Elise Heon's lecture, since it was not only a lecture but they also had a discussion part where the youths were able to ask questions. The participants in Taiwan came from New Zealand, Switzerland, Norway and Sweden, they were guided by youths from Taiwan and learned a lot about daily life in Taiwan.

The programme was arranged by Zane Bartlett from New Zealand with assistance from Caisa Ramshage. Despite none of the organisers being in Taipei during the planning or before, it worked fairly well due to good assistance from Retina Hong Kong and Retina Taiwan who organised the main conference.

There will also be a youth programme at the Retina International conference in Auckland, New Zealand.

3.7 Retina International Operations

3.7.1 Funding and accounts

The budget of Retina International includes four major items:

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

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 our visibility. 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 - 2018.

In order to finance the Dublin office major fund-raising efforts have to be undertaken. Thanks to unrestricted educational grants from F. Hoffmann-La Roche, Novartis and Spark Therapeutics major projects could be executed and thus assist to finance the office in Dublin. With the creation of the Retina International Network Partners (RINP) we do hope to raise additional funding that also can be used as core-funding.

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 did not continue the scientific newsletter. This part of the website will be re-designed should there be additional funds available.

As the conference 2018 is held early in February 2018 it is not possible to organise the auditing of the accounts before leaving for New Zealand. Therefore, the GA will be presented with the accounts such as they will be submitted to the auditors end of February 2018.

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, 50% support would be 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 CEO has continued to work primarily on sustaining the RI Dublin office through securing unrestricted educational grants for specific projects. Some of these projects have allowed us to hire a part time project manager on a part time contract in 2017 and we are currently recruiting a Science Communications officer on a part time contract from January 2018. The CEO hired a part time intern in late 2017 to carry out basic tasks. As the CEO does not have an assistant to date we looked to secure this function through an intern position. We are happy to report that a business graduate from the United States will work with the Dublin team from January to March 2018 as part of a work placement programme. The intern will focus on administrative tasks and it is hoped that this can be a rolling position that will free up time for the president and the CEO to concentrate on the strategic development of the organisation. In order facilitate the appointment of new staff at the Dublin office a new space was rented from June 2017 this is an additional but necessary cost to be covered by fund raising. The Dublin office also facilitates the implementation of the

Marketing and Communications strategy, established new social media platforms and hopes that 2018 will allow for significant work on these areas. It is important that members continue to share their news and information with the RI team to ensure maximum publicity for the Retina Community at large. The Dublin office in collaboration with the Zurich office also works on policy development and is concentrating on issues of diagnosis, access to medicines and the health technology assessment process.

3.7.4 Travel activities of the president and CEO

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

president Travels abroad of 105.5 days

CEO Travels abroad of 55 days

The most important travel commitments were:

- ARVO 2017
- Participation in the EURORDIS Round Table of Companies Conference as a guest speaker. The purpose being the development of a paper on Access to Orphan Drugs
- Meetings for the ERN including the launch in Vilnius and the opportunity to present to the 1000 strong audience on the ERN-EYE
- The Kick off meeting of the ERN-EYE in Tübingen
- Participation in the ERN-EYE Ontology Meeting
- Various Rare Disease Meetings in Europe
- Presentations at the RETINA Dublin Meeting
- Presentations at the Macula Retina European Congress – Seville Spain
- Presentation at the Global BioCapital Meeting of Venture Capitalists in life science as invited speaker – Amsterdam
- Presentations to International Society of Genetic Eye Disease and Retinoblastoma
- Presentation on access to orphan therapies at the meeting of health ministers at the EU Summit in Malta
- Presentation to the Committee of Orphan Medicinal Products as part of an event for the European Presidency
- Presenter Genomics and General Data Protection Regulation (GDPR) Enterprise Ireland Dublin
- Visit to FUNDALURP Chile
- EU Retina 2016 and EU Retina 2017

A list is added to this report. Both, the president and the CEO, are making sure that as much as possible of the travel costs are funded externally. It is expected that RI is present at high level meetings of stakeholders to ensure the views and concerns of the community we represent are noted and most importantly acted upon.

3.8 Support of research applications

MC members were actively involved in preparing several applications for research support by the European Commission. 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 and its CEO to bring clinicians together to apply for the European Reference Centre network initiative (ERN). Deadline for the grant application was 21st of June and in December 2016 we received the news that the application was successful and the ERN Eye would be effective by March 2017. The ERN Rare Eye Disease will improve the care of all patients with rare eye diseases and facilitate the participation in clinical trials.

Patient representatives play a major role in leading and supporting this effort. The CEO and the president attended the first meeting in Tubingen and the president attended the first meeting on Ontology in Mon Saint-Odile in 2017 as well as meeting to develop guidelines in Rome on December 6th and 7th. The CEO in her capacity as Vice-President of Eurordis attended a number of high level meetings organised by the European Commission and Eurordis.

3.9 Retina Europe

In September 2017 the macular organisation Spain together with Retina France organised a meeting in Seville (Spain) with a European reach out. During this meeting they discussed a number of follow-up actions to revitalise Retina Europe.

3.10 Ibero-Latinoamericano Retina

During the FUNDALURP conference in October 2017 the member organisations of Latin America met and decided to strengthen the regional co-operation including all Spanish- and Portuguese speaking countries. A workplan was established and time lines are set.

3.11 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 financial difficulty in 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. In 2017 AMD Alliance ceased operations.

3.12 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 Baltimore 2017. 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 2016 the new CEO, Avril Daly, has started her job and is seeking successfully the funds to assure sustainability of the project. However, I wish not to hide, this is an enormous task and I wish to congratulate Avril Daly for her successful work so far. We are pleased to announce that we are confident that we have with the new instrument of the Retina International Network Partners a system to secure the basis costs for the office in Dublin in the long term.

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. When writing this report, we expect (or hope for) a positive decision by FDA to register the first gene therapy for RPE65. 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.
- Support natural history studies: in order to be able to evaluate the additional value of a possible treatment on the progression of the disease, natural history studies are needed for both disease groups: AMD and inherited retinal degenerative diseases.

- 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.

- Furthermore, we as an organisation have to make sure that our future is bright: Some of the leading people are turning into a certain age group. In long term we have to prepare of change of leadership and generation. Doing this we have to be careful to acknowledge the economic situation that has changed. it is not any more possible for young people to dedicate many days to charitable work. Also, Retina International will have to face the future and to consider if young people that do a lot of charitable work as a volunteer could be remunerated for their loss of gain and secured with the usual insurances.

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 its CEO Kevin Whelan who hosted our CEO within Fighting Blindness Ireland for 18 months.

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 with unrestricted educational grants by Novartis, F. Hoffman-la Roche, Retina Implant AG, Okuvision GmbH and Spartx.

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!

C. F. S. J.

Christina Fasser
President, Retina International

Zurich, November 25th, 2017

Appendix 1 to president's report 2016-2017

Member Organisations

| Country | Status | name of organisation |
|--------------|--------|---|
| Australia | FM | Retina Australia |
| Brazil | FM | Retina Brazil |
| Finland | FM | Retina ry / Retina Finland |
| France | FM | Retina France |
| Germany | FM | Pro Retina Deutschland e.V. |
| Greece | FM | Hellenic Retina Society (H.R.S.) |
| 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 Taipei |
| UK | FM | RP Fighting Blindness |
| USA | FM | Foundation Fighting Blindness |
| Israel | AM | Lirot Association |
| Argentina | CM | Stargardt APNES |
| Chile | CM | FUNDALURP |
| Maroc | CM | Association Retina Maroc |
| Spain | CM | Asociación Macula-Retina |

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|--------------|----|---|
| Belgium | IG | Retina Pigmentosa ASBL |
| Cyprus | IG | R.P. Society Cyprus |
| Cyprus | IG | Pancyprian Organization of the Blind |
| Portugal | IG | Fundación Retinitis Pigmentosa de P.R. |
| Argentina | IG | Fundación Argentina de Retinosis Pigmentaria |
| Canada | IG | The Foundation Fighting Blindness - Canada |
| China | IG | RP Committee - China Association of the Blind |
| India | IG | Retina India |
| Iran | IG | Iran RP Center |
| Israel | IG | NAMAG - Association of AMD patients in Israel |
| Malaysia | IG | Teoh Beng Hian |
| Mexico | IG | Patricia Eugenia Zubirán de Aguilera |
| Philippines | IG | Prof. Froilan P. Inocencio M.D. |
| 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 |
| 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 |
|---------------|--|------------|------------|------|
| Zürich | Novartis Meeting review of projects | 08.08.2016 | 08.08.2016 | 0.5 |
| Copenhagen | Eu Retina Symposium and Meetings | 07.09.2016 | 09.09.2016 | 3 |
| Leiden | Meeting at Proqr | 26.09.2016 | 27.09.2016 | 2 |
| Milano | European Patient Information Summit | 04.10.2016 | 05.10.2016 | 2 |
| Florence | Meeting of Treatamd | 19.10.2016 | 20.10.2016 | 2 |
| Barcelona | AMD Risk Meeting | 24.10.2016 | 27.10.2016 | 4 |
| Washington | PROM Meeting | 07.11.2016 | 10.11.2016 | 3.5 |
| Dublin | Retina Meeting | 10.11.2016 | 13.11.2016 | 3.5 |
| Amsterdam | Kick-off Meeting OcuTher | 12.12.2016 | 12.12.2016 | 1 |
| Zürich | Novartis Payers Meeting | 16.12.2016 | 16.12.2016 | 1 |
| Dublin | CEO meeting | 05.01.2017 | 06.01.2017 | 2 |
| Weggis LU | Talk to international leaders of Hoffmann-La Roche | 18.01.2017 | 18.01.2017 | 1 |
| London | Nanomed Meeting | 05.02.2017 | 07.05.2017 | 3 |
| Geneva | RDI Meeting | 09.02.2017 | 10.02.2017 | 2 |
| Brussels | Eurordis Stakeholder Meeting | 21.02.2017 | 23.02.2017 | 3 |
| Vilnius | Launch ErN | 08.03.2017 | 10.03.2017 | 3 |
| Madrid | IAP and GA coalition Roche | 14.03.2017 | 17.03.2017 | 3.5 |
| Tubingen | inauguration Meeting Tubingen | 24.03.2017 | 25.03.2017 | 2 |
| Tubingen | ERN Board Meeting | 03.04.2017 | 05.04.2017 | 2.5 |
| Brussels | EPF Leadership meeting | 09.04.2017 | 11.04.2017 | 3 |
| Baltimore | ARVO | 05.05.2017 | 13.05.2017 | 9 |
| Kobio Finland | OcuTher Meeting | 06.06.2017 | 08.06.2017 | 3 |
| Basel | Roche Advise on clinical trial patient perspective | 04.07.2017 | 04.07.2017 | 1 |
| Barcelona | EU Retina Symposium and MC midterm Meetings | 05.09.2017 | 10.09.2017 | 5 |
| Leeds | ISGN Talk | 15.09.2017 | 17.09.2017 | 3 |
| Mont St-Odile | ERN Ontology Meeting | 09.10.2017 | 11.10.2017 | 3 |
| Dublin | Retina Meeting | 12.10.2017 | 14.10.2017 | 3 |
| Dublin | EPIS Meeting | 15.10.2017 | 17.10.2017 | 3 |
| Naples | Italian Society of ophthalmic genetics talk | 20.10.2017 | 22.10.2017 | 3 |

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|-------------------|---------------------------|------------|------------|-------|
| Santiago di Chile | Meeting FUNDALURP | 26.10.2017 | 31.10.2017 | 6 |
| Tubingen | Kick off meeting medtech | 04.12.2017 | 05.12.2017 | 2 |
| Rom | ERN Meeting on Guidelines | 06.12.2017 | 07.12.2017 | 2 |
| Eindhoven | Nanomed Mid-term meeting | 18.12.2017 | 19.12.2017 | 2 |
| Dublin | CEO meeting | 05.01.2018 | 07.01.2018 | 3 |
| Auckland | RI meeting | 03.02.2018 | 13.02.2017 | 10 |
| | | | | |
| total | | | | 105.5 |

Travel activities of RI CEO during the term of reporting

| Location | Task | From | To | Days |
|--------------------|----------------------------------|------------|------------|------|
| Copenhagen | Eu Retina Symposium and Meetings | 07.09.2016 | 09.09.2016 | 3 |
| Leiden | Meeting at Progr | 26.09.2016 | 27.09.2016 | 2 |
| Barcelona | AMD Risk Meeting | 24.10.2016 | 27.10.2016 | 4 |
| Washington | PROM Meeting | 07.11.2016 | 10.11.2016 | 3.5 |
| New York | UN Rare Disease Meetng | 11.11.2016 | 11.11.2016 | 1 |
| Dublin | Retina Meeting | 10.11.2016 | 13.11.2016 | 1 |
| Brussels | Eurordis Stakeholder Meeting | 21.02.2017 | 23.02.2017 | 3 |
| Vilnius | Launch ErN | 08.03.2017 | 11.03.2017 | 3 |
| Malto | Council of Health Ministers | 19.03.2017 | 21.03.2017 | 3 |
| Brus EU Parliament | Inauguration Meeting Tübingen | 22.03.2017 | 22.03.2017 | 1 |
| Brussels | EURORDIS BOARD | 23.03.2017 | 25.03.2017 | 3 |
| Tuebingen | ERN Board Meeting | 03.04.2017 | 05.04.2017 | 2.5 |
| Baltimore | ARVO | 05.05.2017 | 13.05.2017 | 9 |
| Budapest | EURORDIS AGM | 18.05.2017 | 21.05.2017 | 4 |
| Barcelona | MC&EURetina | 05.09.2017 | 07.09.2017 | 3 |
| Leeds | ISGN Talk | 14/09/207 | 17.09.2017 | 3 |
| Dublin | Retina Meeting | 12.10.2017 | 14.10.2017 | 3 |
| Brussels | EU Parliament | 17.10.2017 | 17.10.2017 | 1 |
| Saville | Macula Retina | 18.10.2017 | 21.10.2017 | 4 |
| Paris | EURORDIS BOARD | 30.11.2017 | 02.12.2017 | 3 |
| London | RPFBUK | 09.01.2018 | 09.01.2018 | 1 |
| Auckland | RI meeting | 03.02.2018 | 13.02.2017 | 10 |
| | | | | |
| total | | | | 71 |