



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

## **Retina International General Assembly 2014**

Paris (France),

Thursday, June 26<sup>th</sup>, 2014

Location: Hotel Pullman Montparnasse, Paris (France)

Start: 09.00 a.m. end: 06.00 p.m.

Room: Vlaminck Grommaire

### **APPENDIX 03-1**

#### **3.1 President's Report and MC Reports 2012-2014**

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## 1. Introduction

This report covers the activities of Retina International from July 2012 to June 2014. The General Assembly (GA) in Hamburg elected the following officers to the Management Committee (MC):

Christina Fasser (President)  
 Fraser Alexander (New Zealand)  
 Maria-Antonietta Leopoldi (Brazil)  
 Claudette Medefindt (South Africa)  
 Caisa Ramshagen (Sweden)  
 Lorna Rosenstein (Canada)  
 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

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 2012 in Hamburg.

### **3. Term of office report 2012 - 2014**

#### **3.1 Introduction**

At its first face-to-face meeting, held in Hamburg, the MC established an ambitious work plan that gave greater responsibility to individual MC sub-committees. The chairs of the different sub-committees were asked to include in their committees non-MC members in order to improve inclusion of our member organisations and to make use of the precious knowledge among our membership.

Once again, our call for volunteers met with minimal response, reflecting the fact that potential candidates are very involved in their home organisation and that local work takes precedence over RI obligations.

This report is structured along the work plan accepted by the GA 2012 in Hamburg.

No mid-term meeting of the MC was held.

#### **3.2 Membership, Governance and Constitution**

##### *3.2.1 General Information*

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

Emphasis is given to nurture and contact with new and developing members in order to provide them with advice and the support needed to establish a strong organisation of patients with retinal degenerative diseases. At the GA 2014, we will have the pleasure to welcome at least two (2) 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 seems to apply for Argentina.

### *3.2.2 Membership Sub-Committee report*

Member: Claudette Medefindt

#### MEMBERSHIP APPLICATIONS

Documents for membership Application have been sent to:

Association Retina Maroc

China Association of the Blind,

Associazione Pro Retinopatici e Ipovedenti (Italy)

RP Denmark

RP Denmark has replied stating that they will remain an Interested Group.

The other 3 organisations have not replied so at the time of writing no recommendations can be made to the GA from the MC. If applications are made in time for scrutiny an email to the MC for consideration will be made.

#### INTERESTED ORGANISATIONS AND GROUPS

Communication with individuals have been maintained and where possible individuals are encouraged to reach out to other patients in their area to form an Interested Group. Caisa Ramshage, KP Tsang, Maria-Antonietta Leopoldi, Fraser Alexander and of course our president Christina Fasser all do tremendous work in mentoring people in their area of influence to promote membership development.

#### EMAILS REPLIES TO RETINA INTERNATIONAL

Individual Emails were sent to 25 patients from 17 countries:

Algeria, Australia, Bahrain, Congo, India, Iran, Latvia, Nigeria, Pakistan, Palestine, Romania, Saudi Arabia, Tanzania, Thailand, United Arab Emirates, United States, Zimbabwe and 3 queries from gmail or yahoo addresses that did not reply to our emails.

#### MEMBERSHIP STATUS

Full members : 26 (Up from 23 in 2012)

Candidate Members: 5 (down from 6 in 2012)

Interested groups: 11 (down from 14 in 2012)

The change is that members move from IG to CM and then to FM.  
The total is 42 (one less than 2012)  
Associate members:1

## DECISIONS TO BE MADE ON MEMBERSHIP STATUS

Some members have not paid fees or have requested a suspension of fees for economic purposes:  
Portugal, Argentina and India

Johannesburg 27 April 2014

### *3.2.3 Governance report*

Member: Lorna Rosenstein

The main issue relating to governance is the proposal to restructure RI and create a secretariat. This is the subject of a separate paper submitted to the GA.

However this task revealed to be very difficult and will be part of a separate motion within the agenda of the GA 2014.

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.

## **3.3 Research**

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

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

Whenever possible, the president represents and advocates for the needs of patients with retinal degenerative diseases. Among other opportunities, the president had been invited to give a talk at the World Ophthalmic Conference in Tokyo within two sessions dedicated to retinal degenerative diseases. These conferences were video-typed and are available of the WOC website (woc on demand) for educational purposes.

Retina International was asked to be part of the scientific board of two EU funded projects: Treatamd and Drugsford. The projects aim to bring basic research to the bed-side, and to bring drug development to clinical trial, respectively.

Gene therapy trials are taking place and will take place soon. In November 2012, on the initiative of the RI president, representatives of most groups conducting or going to conduct gene therapy trials met in Dublin and discussed the different approaches by regulatory bodies.

The annex on travel activities gives a detailed overview.

### **3.4 Communication and marketing**

Member: Fraser Alexander

#### *3.4.1. World Retina Day 2012 and 2013*

In 2012 we highlighted worldwide epidemiological data and stressed “This is a crucial time for patients, clinicians and research sponsors as comprehensive diagnostic data and clinical trial data have the ability to alter the prognosis for millions of patients who are experiencing sight-loss attributable to retinal disorders.” In quoting Prof Robert MacLaren, University of Oxford, UK and his summary of the steps in planning a clinical trial, we explained how patients can assist with every stage of treatment development.

In 2013 we took a similar approach emphasising the fact that at present there are more than 13 different clinical trials being carried out worldwide to test treatments for different inherited retinal degenerative disorders.

#### *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.

### **3.5 Retina International Conferences**

#### *3.5.1 Germany 2012*

The Retina International Conference was held successfully in July 2012 in Hamburg (Germany). The conference was excellently organised and a great success with 800 participants. The format of the conference was unique for Germany and the contact between patients and scientists was extremely appreciated.

#### *3.5.2 Paris (France) 2014*

The GA 2010 granted Retina France the conference for 2014. The conference is to be held in Paris (France). The local scientific hosts are

Prof. Dr. Dufier and Prof. J. Kaplan, who, together with Eric Moser and the RI president, have established a remarkable programme. We are convinced that the conference will be a great success.

### *3.5.3 Taipei (Taiwan) 2016*

The conference in Taiwan is organised jointly by Retina Hong Kong (RHK) and Retinitis Pigmentosa Taipei (RPTA ).

Retina Hong Kong and Retinitis Pigmentosa Taipei Association have been working closely on organizing of the 19th RI World Congress to be held in 2016. The venue is confirmed at the Taipei International Convention Center (TICC). A Conference Service Company is contracted to start relevant organizing and promotional works in March this year. The local government is discussing the mechanism of subsidy to the Congress that shall be determined in 2015. RHK and RPTA have also approached relevant parties in Mainland China to explore the possibilities of supporting the event by participation in terms of attendants and speakers.

### *3.5.4 Future conferences*

A major task of the President is to be on the constant lookout for member organizations to host the biennial RI conference. It was a long-time strategic goal to reach out to the Chinese population. With the entrance from Retina Taiwan a first step was made. In order to give more importance to the South Asian rim we do hope that New Zealand will apply to host the conference in 2018. Thus the conference will be coming back after 30 years to the region.

## **3.6 Youth**

Member: Caisa Ramshagen

During the Retina International conference in Germany there was a parallel youth program with many different activities such as self defence, mobility, sightseeing in the harbour of Hamburg and a special science session at the University clinic in Eppendorf. The last days of the youth program was integrated with the ordinary Retina International Conference. The youth program was much appreciated and the participants came from an Australia, New Zealand, Japan, Finland, Norway, Sweden and Germany.

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

## **3.7 Retina International Operations**

### *3.7.1 Funding and books*

The budget of Retina International includes three major items:

- Basic running costs (phone, mailing, stationery, travel costs)

- Costs of assistants
- The Retina International scientific newsletter

The MC and the president tried to be very thoughtful about the spending and stayed within the budget, allowing increasing 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 to 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.

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

The MC is sensitive to the fact that many of our member organizations are facing difficult economic times. However, for the budget 2015/2016 we will have to once again apply the 15 % increase.

The Hamburg GA decided that we should provide a transfer to accrued accounting. The president has fulfilled this task and the balance sheet 2013 is presented in the new format.

### *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%. 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 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 84 days

The most important travel commitments were:

ARVO 2013

ARVO 2014

Travel to Cleveland to honour Prof. Joe Hollyfield

Several travels to France for preparation of the RI conference

Travel to Tokyo for the WOC conference

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 making things happen.

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

## **3.9 Retina Europe**

Report by Rainald von Gizycki

Encouraged by the positive discussion about Retina Europe at the General Assembly of Retina International in Hamburg 2012 Eric Moser (President Retina France), Viviane Tordeurs (President Retina Belgium) and Rainald

von Gizycki (Honorary President Germany) met in Paris to discuss the possibility of relaunching Retina Europe.

As a first step, a questionnaire concerning the interest of national members of Retina International in Retina Europe was designed and sent by Eric Moser to 16 colleagues. We wanted to find out in how far the European Retina associations share common goals and want to carry out bilateral or common projects and activities in the future.

Only six out of 16 associations filled out the questionnaire, a rather disappointing result from our point of view. At the GA in Paris, we will present more detailed results of the questionnaire analysis. We will suggest that a core group of a few Retina Europe associations will continue to cooperate among themselves in the name of Retina Europe.

### **3.10 AMD Alliance**

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

The mission of AMD Alliance International is:

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

Initial target audiences and focus areas are:

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

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

AMD Alliance undertook a review in order to streamline decision making and thus enable the organisation to react quickly to new developments. 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.

### **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 Seattle 2013 and in Orlando 2014. 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. However, no funds were allocated for this ambitious project. Real life showed that a number of potential sponsors were ready to commit themselves, but first wanted to see the structure installed. Therefore, this project is again the object of discussion at the GA 2014 in Paris and hopefully will be allocated the necessary resources.

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 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 and Anna Moran who took on the difficult task to try to set up the Retina International office.

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 wish to acknowledge the Swiss Federation of the Blind and Visually Impaired; who provide us with our facilities at no cost and allow us to utilize their infrastructure. I also wish to thank the Japanese RP Society who financed the travel costs to the WOC 2014 in Tokyo allowing RI a special

visibility. Thanks to the educational grant by Richard Crump we will be able to finance part of the travel costs for new member organisations attending a Retina International Conference for the first time.

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 15th, 2014

## Appendix 1 to president's report 2012-2014

### Member Organisations

Country	Status	name of organisation 1	last update	Total Patients	Donors	Others	members
Argentina	CM	Fundación Argentina de Retinosis Pigmentaria	none				
Chile	CM	FUNDALURP	none				
India	CM	Retina India	none				
Iran	CM	Iran RP Center	2011	4500	3300	0	1200
Spain	CM	Fundación Retina España	2011	2540	2500	30	10
Australia	FM	Retina Australia	2014	4500	1500	3000	900
Belgium	FM	Retina Pigmentosa ASBL	2014	180	120	4	0
Brazil	FM	Retina Brazil	none				
Canada	FM	The Foundation Fighting Blindness - Canada	2011	25200	3700	23000	0
Finland	FM	Retina Finland	2014	675	583	0	92
France	FM	Retina France	2014	19650	5870	13768	0
Germany	FM	Pro Retina Deutschland e.V.	2011	5782	4589	568	625
Greece	FM	Hellenic Retina Society (M.E.A.)	2011	450	440	10	0
Hong Kong	FM	Retina Hong Kong	2011	684	527	109	48
Iceland	FM	Retina Iceland	2014	63	63	0	0
Ireland	FM	Fighting Blindness	2014	10918	676	10018	0
Italy	FM	Retina Italia (Onlus)	2007	700	700	0	0
Japan	FM	JRPS	2011	4027	3800	131	96
Netherlands	FM	Eye society Netherlands, Retina Group	2014	1486	1486	0	0
New Zealand	FM	Retina New Zealand Inc.	2010	370	350	30	20
Norway	FM	Retinitis Pigmentosa Foreningen i Norge	2014	737	586	0	151
Pakistan	FM	Pakistan Foundation Fighting Blindness	2008	2890	2800	90	0
Portugal	FM	Associação de Retinopatia de Portugal (ARP)	2011	1555	1357	198	0
South Africa	FM	Retina South Africa	2014	2720	2060	200	460
Spain	FM	FARPE	2011	7673	7000	598	75
Sweden	FM	Svenska RP-Föreningen	2009	540	500	0	40
Switzerland	FM	Retina Suisse	2014	1275	1001	167	107
Taiwan	FM	Retinitis Pigmentosa Foundation Association in Taiwan	2014	627	458	46	32

UK	FM	RP Fighting Blindness	2014	1,000 people	1000	4000	5000
USA	FM	The Foundation Fighting Blindness Inc.	2014	635829	312588	96418	323241
China	IG	RP Committee	none		600000	0	0
Cyprus	IG	Pancyprian Organization of the Blind	none				
Denmark	IG		none				
Hungary	IG	"For Our Sight" Foundation	2007	2800	1500	1000	0
Hungary	IG	Retina Hungary	2008	330	300	10	0
Israel	IG	NAMAG - Association of AMD patients in Israel	none				
Malaysia	IG		none				
Mexico	IG		none				
Netherlands	IG	NVBS / Retina Belangen	none				
Philippines	IG		none				
Rumania	IG	Pro Oculo Pro Viso FO ROMANIA	none				
Singapore	IG	Eye & Retina Surgeons	none				
Singapore	IG	Retinitis Pigmentosa Society (Singapore) / RPSS	2007	388	334	0	54
South Korea	IG	Korean Retinitis Pigmentosa Society (KRPS)	none				

## Appendix 2 to president' s report 2012-2014

### Travel activities of RI president during the term of reporting (15.07.2012 - 26.06.2014)

Start	End	Location	Objective	Days	Funds
10.07.2012	16.07.2012	Hamburg (Germany)	RI Conference, MC Meetings	6	RI
17.07.2012	21.07.2012	Regensburg (Germany)	RD Meeting	4	private
05.09.2012	07.09.2012	Tubingen (Germany)	Drugsford Meeting	3	Drugsford Project
08.10.2012		Paris (France)	Engage Eye Research	1	funded
08.11.2012	11.11.2012	Dublin (Ireland)	Science Conference, AGM (talks)	3	funded
26.11.2012	28.11.2012	Geneva (Switzerland)	TREATAMD meeting	3	funded
27.01.2013	27.01.2013	Paris (France)	Meeting with Retina France	1	RI
28.01.2013	30.01.2013	Paris (France)	Evaluation Institute de la Vision	3	funded
13.02.2013	14.02.2013	Brussels (Belgium)	Tretush Project midterm meeting	3	funded
20.02.2013		Schlieren (Switzerland)	ESPATEC/Novartis talk to leaders of Novartis research unit	1	funded
06.03.2013	08.03.2013	Modena (Italy)	Drug ford meeting	3	funded
16.04.2013	18.04.2013	Dublin (Ireland)	Eurordis / conference, IRDIC conference, talk with Fighting Blindness	3	partly funded
03.05.2013	11.05.2013	Seattle (USA)	ARVO, SMAB meeting, conference preparation, contact to researchers	8	RI
23.05.2013	25.05.2013	Dublin (Ireland)	IRDIC/EPF	3	partly funded
31.05.2013	02.06.2013	Florence (Italy)	Italian Society of Ophthalmology, talk	3	funded
04.06.2013		Brussels (Belgium)	Shyer Symposium reimbursement rare disease drugs	1	funded
25.08.2013	27.08.2013	Lund (Sweden)	Drugsford meeting	3	funded
08.09.2013	09.09.2013	Paris (France)	Hospital Necker, preparation of rib conference	2	RI
12.09.2013	16.09.2013	Cleveland (USA)	Symposium honouring Prof Hollyfield	4	RI
07.11.2013	10.11.2013	Dublin (Ireland)	Talks at the Science meeting and Patient Meeting	3	partly funded
24.11.2013	25.11.2013	Paris (France)	Tretush Project Final meeting	2	funded
28.11.2013	28.11.2013	Paris (France)	RI conference preparation	1	RI
05.12.2013	06.12.2013	London (UK)	AMD Alliance Board Meeting	2	partly

21.01.2014	22.01.2014	Paris	Meeting conference	2	funded
25.02.2014	28.02.2013	Leiden Netherlands	Drugsford meeting	4	RI funded
30.03.2014	06.04.2014	Tokyo (Japan)	talk at WOC, meeting with JPRS and RP Taipei	7	funded
02.05.2014	09.05.2014	Orlando (USA)	ARVO, SMAB meeting, conference preparation, contact to researchers	7	RI
02.06.2014	02.06.2014	Basel (Switzerland)	Novartis, Welcome day for management talk	1	funded

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