



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

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## **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.

### **Appendix 06-2**

6.2 Retina International Secretariat and president' s office: Work plan 2018-2020: Objectives, mile stones and outcomes (appendix 06-2)

#### **Overview**

Retina International is governed by the management committee and the president who are in turn supported by a part-time staff member (25 %). A full time CEO works on the delivery of the agreed work plan with the support of a part time project manager and will recruit a part time Science Communications Officer in 2018. The MC, president and CEO work with the help of sub-committees in the area of research, membership, fundraising, audit and financial oversight, human resources and marketing.

A mid-term meeting of the MC was held in September 2017 in Barcelona Spain, an MC meeting will also take place during the RIWC in February 2018. As the next RIWC will take place in September 2020, it is proposed that a midterm meeting of the MC should be held in March 2019 where all relevant matters will be discussed and the workplan and strategy reviewed. At these meetings the work in progress will be assessed and the targets readjusted if necessary.

*The work in progress covers the following areas:*

1. Sustainability of Retina International office through fundraising
2. Membership
3. Research

4. Communication and marketing
5. Capacity building
6. Congresses
7. Constitution and policy
8. Youth
9. Finances and administration

Detailed work plan

## **1. Sustainability of Retina International office**

### *Objective*

- To develop and appropriately manage and grow the RI Office the next three years in order to achieve its objectives.

### *Actions*

- To establish a strategy and working plan following discussion with the MC

### *Activities*

- Work to assure the sustainability of RI through the development of a robust financial strategy as well a comprehensive workplan that will be developed with the MC, president and CEO for presentation at GA 20

## **2. Membership**

### *Objective*

- Keep contact with existing membership and stimulate new member organisations

### *Action*

- Reinforce relationship between Retina International and its member organisations by providing the appropriate support and services
- Pay attention to issues that may arise with existing members as technologic advances in retinal research and development continues to grow
- Target Latin America and South-East Asia in order to attract new member organisations.
- Target areas in Europe that do not currently have representation by a patient organisation.

### **3. Research**

#### *Objective*

- To promote, stimulate and support the progress of research and development in retinal degenerative diseases

#### *Actions*

- Maintain close co-operation with Retina International SMAB
- Organise annual SMAB meeting in co-operation with the chair of the SMAB
- Disseminate on-going research and latest research results
- Where appropriate help to facilitate the development and fulfilment of multinational treatment trials in inherited retinal diseases through early dialogue and collaboration with stakeholders
- Cooperate with new and existing industry partners in the field of translational research for IRDs
- Support projects and ongoing activities with EU and similar government funding agencies and organisations in Australia and New Zealand, Asia, Latin America and USA as well as Africa.
- Participate in European Patient Forum (EPF)
- Cooperate with global rare diseases organisations such as Rare Disease International and its partners.  
Where appropriate cooperate with learned societies and institutions such as ARVO, ESHG, EURetina, DIA, EMA and FDA etc.
- Cooperate with ongoing research projects as advisors and representing the view of patients  
Support research initiatives and consortia during grant application as well as evaluation processes

### **4. Communication and marketing**

#### *Objective*

- Establish Retina International as the leading organisation for supporting research in retinal degenerative diseases and providing patient information

#### *Actions*

- 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,
- Develop a process to regularly update the RI website for maximum impact and to attract regular visitors

- Develop and implement a Social Media policy
- Through membership develop a cohort of contributors to provide information to the site including Wikis and Blogs
- Implement a simple process to respond in a timely fashion to personal enquiries
- Publish Retina International statements and press releases for use by member countries
- Develop a cohort of key opinion leaders drawn from the membership, SMAB and learned societies to opine on developments within the research and development space
- Develop and implement a house style to be used in all communications materials to ensure accessibility and brand identification

## **5. Capacity building – Education and Outreach**

### **Objective:**

- To facilitate the upskilling of Retina International Members through the development of bespoke capacity building and bespoke education programmes at a time of significant activity in retinal research and innovation development

### **Actions:**

- RI is seeking funding for specific projects that are highlighted as a need by our membership this include ongoing projects listed and future topics
  - Patient Reported Outcome Measures Project - PROMs
  - A preliminary multi stakeholder meeting on PROMs took place in Dublin, Washington DC and Baltimore MD in 2015/2017 work ongoing to have paper prepared for publication in 2018.
  - Work will continue in developing patient advocates to participate in ERN-EYE (European Reference Network for rare eye disease. Representation of RI community across committees. Resources need to be sought to develop education and communications tools for patients and their families – these will benefit global community.
  - Ensure that toolkits such as Genetic Testing Toolkit and AMD Toolkit are kept updated and current.
  - Development of Community Advisory Boards one in AMD one in IRDs to work with industry partners.

- Development of the Retina International Network of Partners (RINP)
- *Seek further funding for educational toolkits such as:*

### **5.1 Understanding Retinal diseases**

- a) Rare and genetically inherited eye disease
- b) Age related common eye diseases

### **5.2 Infrastructure Development around:**

- a) Genetic Testing (ongoing)
- b) Clinical Trials
- c) Patient Registries

### **5.2 Regulatory Framework**

- c) Health Technology Assessments
- d) Off-label Medicines

### **5.4 Legislation and Policies**

- e) Access to new medicines
- f) Reimbursement

### **5.5 Working with Industry**

- a) Community Advisory Boards

## **6. Congresses**

### *Objective*

- Organise and support the Retina International World conference 2020

### *Actions*

#### **6.1 Congress 2020 – Iceland**

- Accept business plan
- Accept budget & costs
- Assist with the development of the program, the identification and approach to speakers with recourse to advice and approval of Retina International Scientific and Medical Advisory Board
- Composition of Continuing Education Program, General Assembly and project meetings

#### **6.2 Congress 2022**

- Define strategic targets for 2022 conference
- Support the organiser 2022 in establishing business plan, speakers program, allocation and financing as set out in congress rules

### **6.3 Congress 2024**

- Work with members potentially ready to apply for the conference at the GA 2020
- Work with members in development of promotional tools and materials for congress.

## **7. Constitution and policy**

### *Objective*

- Take up procedures that need clarification in policy or constitutional matters

### *Actions*

- Regular overview of present policies and formulation of new policies that may be needed in light of the status of the secretariat
- Develop guidelines and auditing procedures to guarantee correct and smooth running of the affairs
- Be mindful of new and development governance practices in the NGO/Charitably sector to ensure compliance at all times

## **8. Youth**

### *Objective*

- To stimulate young leadership among Retina International membership and within Retina International

### *Actions*

- Review the youth membership and establish how/why certain countries are in a position to attract youth involvement over others
- Work with MC and targeted youth leaders to develop a youth strategy that takes their opinion and needs into consideration and appoint a youth leadership team that will liaise with MC point of contact
- Work with member organisations to establish and support an official youth contact in each country
- Provide youth information on Retina International website & link to youth website
- Encourage Member Organisation to include youth meetings to coincide with their meetings and congress as is the case at RIWC

## **9. Finances, Administration & HR**

### *Objective*

- Guarantee the functioning of Retina International activities

### *Actions*

- Oversee & collect membership fees
- Evaluate continuously the fee structure and impact on members
- Develop budget for next period in conjunction with the MC, president and CEO
- Maintain and develop RI membership database and administrative infrastructure
- Work with the RI Scientific and Medical Advisory Board in organising the SMAB meeting
- Assist the MC in organising meetings
- Work with MC sub-committee, president and CEO when needed on HR issues particularly in any future recruitment to fulfil growing office
- Work with the MC to assure the challenge of future generation change within the RI leadership.

**December 5, 2017**