



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 end: 17.00

### **APPENDIX 08-2**

#### 8.2 Website

**Motion: The MC moves to accept the report of the CEO.**

#### **Report on Website Development**

Retina International received an unrestricted grant to support the development of a new state of the art website which was facilitated by Dara Creative an award-winning Web Development Company based in Dublin and launched on World Retina Day, September 24, 2017.

The primary function of the site is to efficiently provide networking opportunities, research updates, and news items on therapy development to member groups while also being central to the further development of our global community and the facilitation of capacity building programmes.

Although it is designed as a tool for member organisations we know that it utilised by scientists and clinicians who access its research database.

The website was built on a drupal platform to allow for easy expansion of the site. This format was recommended by members such as FFB and ProRetina Germany as a good structure to fulfil our needs.

The website was designed by Mark Mulhall and built by Matthew Stocker of Dara Creative Dublin, both of whom were passionate about the site and went above and beyond to deliver it on time. Unfortunately for me both left Dara Creative one month after the site was delivered.

Website upkeep is critical yet expensive resource to keep updated and fresh. Charities are expected to have well-functioning up to the minute websites and this cannot always be achieved without ongoing financially and in-kind support.

It was critical from the outset that the positivity and dynamic nature of the community is reflected in the website, I do not believe that since its launch last year the website has achieved its full potential or been given enough focus. This is due to resource issues and also the support company (Dara Creative) having had many staff changes. I do not believe purely reactive site is of value, it needs to be more proactive and better utilised.

To address this a number of steps have been taken and the results will be applied from 2018. A RI is recruiting a part time Science Communications Officer to be in place January 2018. This post holder will be dedicated to the development of the website and associated online tools. The RI team and the support company will have a regular monthly call to agree priorities for the site on a month to month basis and in line with our overall communications strategy. There will be months where the site will require a lot of work and others when the needs will be less. Having a resource to take 'ownership' of the site will be an advantage.

With the recruitment of a Science and Communications officer we believe a more hands on approach to dealing with the service provider will lead to a much more dynamic and focused site. Used appropriately it should then achieve its potential of becoming a global hub of trusted and useful information.

We will regularly interact with our membership to highlight and promote their various activities and include their work in our new monthly E-newsletter.

**Training:** Although a dedicated resource will be employed to manage the site, all staff members of RI will be trained in basic management of the site and an agreed process of updating and will be implemented. To maximise limited resource, staff members will have responsibility for specific tasks, for example, administration will upload documents to the private members section including GA documents and the like. A guidance document will be issued to all staff members to allow them to easily access and manage the site.

**Toolkit Development:** Drupel allows for ease of expansion and so future on-line toolkits will be developed to complement the look and feel of our site.

**Developing voluntary groups and foundations:** One of the key reasons for the development of the website is to facilitate

communications between member organisations. Our new site should also be used for us to advise and encourage the development of emerging groups and potentially to match new organisations with existing ones in a mentoring programme that could be facilitated through the website.

**Newsletters:** A content management system for the development and circulation of e-newsletters is already part of the system and when a coordinated process of distribution is agreed we will utilise this for streamlined communications.

**RI TV:** RI have already created a YouTube Channel. This will be better utilised and uploaded with RI developed content as well as other useful videos from member organisations, research institutions as well as learned societies and industry.

**Social Media:** RI has a presence on Facebook and Twitter. These will be linked to the site.

**Survey Monkey:** RI has used survey monkey successfully this year and plan to do more with this resource in the coming year. This is a great way of getting to know the membership better as it evolves and its needs and aspirations change.

**Avril Daly**  
**December 5, 2017**