**RETINA AUSTRALIA**

**CHAIRMAN’S REPORT 2018-2019**

It is my pleasure, on behalf of the Board of Retina Australia, to present the 2018-2019 Annual Chairman’s Report. In doing so I would like to thank my fellow Board members: Jeremy D’Souza, Rosemary Boyd, Noel Burton, Melanie Chatfield, Robert Craft, Julie Demarte and Peter Maas, along with all of our other volunteers, for their invaluable support and contributions during the year.

I would also like to express our appreciation to Anne Housego and Robin Poke, who resigned from the Board during the year for personal reasons, for their contribution, and wish them well for their future endeavours.

Throughout the previous twelve months the Board has spent a great deal of time planning for, and implementing, all of the steps necessary to complete the amalgamation of all of the former state and territory organisations with Retina Australia. It is truly exciting to embark on the beginning of a new era for Retina Australia.

As members would be aware, following much deliberation, the members of Retina Australia voted unanimously for the amalgamation on 13 October 2018. The resultant revamped national organisation officially commenced operation on 1 January 2019. This is an extremely significant time in the history of Retina Australia and congratulations must go to all members and teams in each state and territory who worked so hard to bring about this proposal for a united national body.

Following the amalgamation, individuals, rather than states and territories, will be members of Retina Australia. As a transitional arrangement, all existing individual members in the states and territories were automatically accepted as members of Retina Australia. Memberships with the new national body will be renewable annually by 30 June each year. The Board would like to see all former members of individual state or territory groups formalising their membership and paying their annual subscriptions to Retina Australia by 30 June 2020.

One of the great advantages of the amalgamation is the streamlining of our management and removal of duplicated services. Although the administrative operations for the revamped national organisation commenced from 1 January 2019 with the establishment of an office in Ross House, Flinders Lane, in the Melbourne CBD, there is still more work to be done in winding up the separate formal operations of each of the state and territory groups. The Board is looking forward to seeing these actions completed, so that it can fully focus on the future.

Another aspect of the amalgamation has been the process of applying for fundraising approvals in each state and territory. These approvals have now been obtained and consequently fundraising activities can now be planned and executed across Australia for the national organisation.

I believe that the amalgamation will help realise the aims and objectives of Retina Australia in our bid to fund research that may ultimately lead to a treatment or cure for inherited retinal diseases. The amalgamation will also simplify and reduce external reporting and regulatory obligations, simplify the overall governance arrangements for member stakeholders; and provide a stronger and unified voice to assist in relation to advocacy issues with Government. It will enable our members to focus on fundraising and social activities under the umbrella of the national organisation with a reduced administrative burden.

As I have previously stated, “we see that nationalisation is an exciting opportunity, and with the potential of establishing a more powerful national voice, we would be hopeful of reaching out to, and supporting, many more individuals and families”.

**ANNUAL GENERAL MEETING 2018**

Retina Australia held its 34th Annual General Meeting (AGM) of its then state and territory members at the ibis Hotel & Apartments, Melbourne on Saturday 13 October 2018. Representatives present were provided with reports of the year’s activities of Retina Australia and of each of the state and territory associations, along with the 2017/18 audited financial statements.

Collectively these reports highlighted the time and energy spent by our former volunteer boards and management committee members throughout Australia, as they worked to support people affected by inherited retinal disease. There were many fundraising activities, varying from tin collections, fun runs and antique fairs to workplace giving programs and annual donor appeals. Social events such as morning teas or coffee groups also remain popular across the country. It was clear however, from the reports, that organising fundraising and social activities is becoming more challenging in the charity space due to declining member engagement, a difficult economic climate and a general reluctance to volunteer. Now following the amalgamation, we look forward to members in the states and territories being able to more easily arrange fundraising and social activities in their own state and territory.

**CONSTITUTION**

The new Retina Australia Constitution was unanimously accepted by members at the 2018 AGM. This document sets out the governance details for the newly restructured national organisation; however, the objectives and vision of Retina Australia remain the same. Directors remain steadfast in our aim to work towards “a world without inherited blindness”.

I would like to thank Rosemary Boyd for her considerable contribution in overseeing the process for the development of the new constitution and in making sure that it satisfied all regulatory requirements.

**DONATIONS & FUNDRAISING**

The Board is extremely grateful for all donations, as these fund Australian research into inherited retinal disease, and help us to support members and the newly diagnosed.

During the financial year, Retina Australia received donations from state and territory organisations as well as from individual members and friends. Donations have also been provided through regular monthly credit card donations, via the website, and through an automatic pre-tax salary deduction contribution via “Good2Give” and other workplace giving programs. The Board is hopeful that donations through workplace giving programs will grow as Retina Australia becomes more well known among companies that participate in workplace giving programs.

Overall Retina Australia received donations of $119,000 in the 2019 financial year. These funds and some of our accumulated funds were combined to commit almost $160,000 to the 2019 Retina Australia Research Grants pool. We would like to thank all of our donors most sincerely for their generosity: it is beneficial to all of us, and very much encourages the research grant recipients to pursue research into inherited retinal diseases.

Apart from the various ways in which Retina Australia receives donations, our fundraising has included the sales of owl merchandise and Entertainment Books. Although the income generated from these activities is a little sporadic, more than $2,100 was raised during the financial year from these activities.

**RESEARCH GRANTS**

Congratulations to Dr Livia Carvalho from the Lions Eye Institute in Perth, Professor Nigel Lovell from the University of NSW, Dr Michael O’Connor from Western Sydney University and Dr John De Roach from the Australian Inherited Retinal Disease Registry and DNA Bank for being awarded Retina Australia Research Grants for 2019. These grants have a total value of $159,900. This brings the total amount provided by Retina Australia for research, since these grants were established twenty years ago, to more than $5.5 million dollars.

**MEMBERSHIP**

As previously mentioned, all former members in every state and territory were automatically accepted as Associate Members of Retina Australia upon amalgamation. Recently we contacted all these members to invite them to become either Associate Members, or Members with full voting rights, of Retina Australia. The income received from membership fees assists Retina Australia to continue services to members and maintain the national office.

**AUDIT & FINANCE**

Attached to this report are the audited financial statements for the financial year July 2018 to June 2019.

Mr Tony Ager, director of Assur Pty Ltd undertook the audit, and he has stated in his report that the annual financial statements give a true and fair view of the company’s financial position and comply with the Australian Accounting Standards and the Australian Charities and Not-for-profits Commission Regulations 2013.

Although these statements show that during the financial year Retina Australia accrued a deficit of $55,588, it is important to note that this overall loss was incurred because reserve funds were used for research grants, and some additional expenditure was incurred in making the transition to the national organisation. All of the regular administration expenses were within budget. It is also clear from the Balance Sheet that Retina Australia is in a financially sound position with assets of more than $690,000.

**COMMITTEES & WORKING PARTIES**

In order to assist the Board with their work in overseeing the governance and organisation of Retina Australia, several ongoing committees were established during the year.

These are:

1. Finance & Risk Committee
2. Communications Committee
3. Member & Community Engagement Committee
4. Marketing & Fundraising Committee
5. Strategic Advocacy Committee

Board members have been allocated specific portfolios and will convene these committees, seeking other volunteers to assist with this work.

**NEWSLETTER**

The publication of a quarterly national newsletter, “Retina Australia News”, in three formats, which commenced in December 2016, continues to be a huge success. The distribution of this newsletter enables us to inform members about research occurring world-wide and stories from around the globe. It is pleasing that members have also provided articles for inclusion.

**WEBSITE**

It is exciting to be able to report that the new Retina Australia website, <https://www.retinaaustralia.com.au> has been launched. The site includes information about Retina Australia, descriptions of the varying types of inherited retinal diseases and up-to-date research material. There are also links to social media such as Facebook and Twitter and a “donate now button” where donations can be made online, directly to Retina Australia.

I would especially like to thank Mary-Anne Carmody for her significant contribution in editing and preparing the draft website leading up to its launch and to acknowledge the work of the website working party who contributed to this project during the previous two years.

**FRIENDS OF RETINA AUSTRALIA**

As part of the restructure, it was envisaged that “Friends of Retina Australia” groups would be established to provide mutual support for those affected by inherited retinal diseases; raise money for research through organising fundraising events; enable members and friends to meet socially; and raise awareness of Retina Australia. A “Friends of Retina Australia” group has been established in Perth and others are in the planning stage. These social groups will be critical to the future of Retina Australia and we look forward to hearing from individuals or groups wishing to organise events at a local, state or territory level.

**RETINA INTERNATIONAL**

Retina Australia is one of the 34 world-wide organisations who are members of Retina International. My role as a vice president of this organisation this year has been to contribute to various working parties established to canvass the views of members; to collect data from member countries about services available for people affected by inherited retinal diseases; and to contribute to four online educational toolkits aimed at assisting people around the world living with inherited retinal disease.

**GLOBAL RESEARCH**

In recent months, the Retina International Scientific and Medical Advisory Board met in Honolulu. Professor Erica Fletcher from the University of Melbourne and Professor Michael Kalloniatis from the Centre for Eye Health, Sydney, represented Retina Australia. At the meeting, speakers from across the globe provided updates about fifteen clinical trials which are underway. It is certainly an exciting time for research, and great advances are being made.

**VISION 2020 AUSTRALIA**

As part of our membership of Vision 2020 Australia we have continued to work with its Prevention and Early Intervention Committee and the Independence and Participation Committee. These committees meet to discuss ways in which they can lobby government and work with their members to provide support for Australians with all manner of eye conditions including those with inherited retinal disease.

**IN CONCLUSION**

Following an eventful year in which we achieved the amalgamation of the state and territory members of Retina Australia into a truly national body, I am hopeful that we will be able to have new vigour in pursuing our mission of “assisting those affected by vision loss from inherited retinal diseases by providing support, information and funding for research”. We look forward to the new year with enthusiasm.

**LEIGHTON BOYD**

**19/10/2019**