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CHAIRMAN'S REPORT

I am very pleased to report that after considerable consultation, and discussion, the members of Retina Australia, which include the incorporated associations in Western Australia, South Australia, Victoria and the Australian Capital Territory, have voted unanimously to amalgamate with Retina Australia. The resultant revamped national organisation is planned to take effect from the 1st day of January 2019.

This is an extremely significant time in the history of Retina Australia. I would like to express my thanks, and congratulations, to all members and teams in each state and territory who have worked so hard to bring about this proposal for a unified national membership organisation. As I have mentioned previously, "the Board sees that amalgamation is an exciting opportunity with the potential of establishing a more powerful national voice, with a goal of reaching out to, and supporting, many more individuals and families in a consistent manner".

As a result of this amalgamation, members in every state and territory, namely Western Australia, South Australia, Northern Territory, Victoria, New South Wales, Queensland, Tasmania and the Australian Capital Territory, will automatically be accepted as members of Retina Australia. During the coming months we will be contacting all members to check that we have their up to date information and preferences for the format for receiving information and the newsletter.

MEMBERSHIP

Early next year, and prior to the end of this financial year, members will be invited to renew their membership by either:

- (i) Paying \$30 to become an Associate Member which will provide you with the quarterly newsletter, Retina Australia News, in your preferred format, and the support and information which has previously been available through the local state and territory organisations; or alternatively
- (ii) Paying \$50 to become a Member with full voting rights, which will enable you to participate at general meetings and be eligible to nominate, or be nominated for, a position on the Retina Australia Board as well as receiving all the benefits of an Associate Member.

Membership will be renewable annually. The membership subscription dues will assist Retina Australia to continue our services to members, and maintain a national office. In particular, these subscriptions help us to cover such things as the costs of the newsletter, telephone-based peer support, printing and posting information pamphlets, information kits, rent and staff wages.

OFFICE

The first Retina Australia office is scheduled to be established in January 2019. The location and contact details follow.

Address: Ross House

247-251 Flinders Lane

Melbourne VIC 3000

Phone: 03 9650 5088

Toll Free: 1800 999 870

Email: info@retinaaustralia.com.au

Initially the office will be open on Tuesdays and Thursdays between 9:30am and 3:00pm, however you will be able to leave phone messages at any time as these will be checked regularly. We hope that these hours may be extended in the future.

ANNUAL GENERAL MEETING

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

Collectively these reports indicated the significant time and energy spent by our volunteer boards and management committee members throughout Australia, as they worked to support persons affected by inherited retinal disease. Fundraising activities were numerous and vary 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 remain popular across the country. It is clear however, from the reports, that organising fundraising and social activities, is

becoming more challenging in the charity space due to declining member engagement, difficult economic climate and a general reluctance to volunteer. As a result of the election held during the AGM, and of Board appointments for directors, the composition of the Retina Australia Board for 2018-2019 is:

Chairman: Leighton Boyd

Deputy Chairman: Jeremy D'Souza

Company Secretary: Rosemary Boyd

Board Members: Noel Burton, Melanie Chatfield, Robert Craft,

Julie Demarte, Peter Maas & Robin Poke

During this meeting, the members voted for the amalgamation to proceed and to target an effective date of 1st January 2019.

CONSTITUTION

The new Retina Australia Constitution was unanimously accepted by members at the AGM. This document outlines the governance details for the national organisation. In due course a copy will be uploaded to the new website, however if any member would like a copy, please contact the office and we will be pleased to forward one to you.

RESIGNATION OF BOARD MEMBER

At a recent Retina Australia Board meeting, it was with regret that Board members accepted the resignation of Anne Housego. Anne, formerly the President, and office administrator, of Retina Australia (Queensland), found that due to personal circumstances she was no longer able to continue on the national Board. Anne first joined the national Board in 2007, and during the previous two years was an editor of Retina Australia News as well as our audio newsletter narrator. On behalf of the Board, and all members across Australia, I would like to thank Anne most sincerely for her contribution to the Board and for her significant support to our members in Queensland.

RESEARCH GRANTS

I would like to congratulate 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 million dollars.

Dr Carvalho's project is entitled "Dual AAV retinal gene therapy approach for Usher 1F treatment"; Professor Lovell will be studying the topic "Improving the global acceptance of retinal prostheses: Assessing the influence of different stages of retinal degeneration on selective activation of retinal ganglion cells"; and Dr O'Connor will be investigating "the mechanism by which C.1 rescues some functions in Best Disease Retinal Pigment Epithelium". The Australian Inherited Retinal Disease Registry and DNA Bank team under the leadership of Dr De Roach will continue their maintenance and development of the Registry and DNA Bank. The Board and I look forward to hearing reports of this work over the next twelve to eighteen months.

COMMITTEES & WORKING PARTIES

In order to assist the Board with their work in overseeing the governance and organisation of Retina Australia, a number of ongoing committees have been established.

These are:

- (i) Finance & Risk Committee
- (ii) Communications Committee
- (iii) Member & Community Engagement Committee
- (iv) Marketing & Fundraising Committee
- (v) Strategic Advocacy Committee

Working parties may also be created for a specific time period to manage individual projects. Board members will be allocated specific portfolios and will convene the committees, or working parties, and will be seeking volunteers from the members of Retina Australia to assist with this work. Meetings will generally be held by teleconference at mutually convenient times.

Further information about these committees will be circulated in future editions of Retina Australia News. However, if you have an interest in being involved in the work of Retina Australia by joining one of these committees, please do not hesitate to contact the office by phone or email.

WEBSITE

I am extremely hopeful that despite the number of setbacks with the construction of the new website, it will be finally launched on 1st January 2019. We look forward to your feedback regarding the site after this time.

FRIENDS OF RETINA AUSTRALIA

The Board of Retina Australia are very keen for members to establish groups of individuals who are interested in being affiliated with Retina Australia. These groups would provide mutual support for others affected by inherited retinal diseases; meet socially; raise awareness; and potentially raise money through organising fundraising events. Groups can be formed in cities, country towns, or regional locations as well as for specific mutual interests. If there are two members, or more, in your area interested in establishing a group of “Friends of Retina Australia”, please contact the office for more information about the application process.

Members can still fundraise for Retina Australia outside of a “Friends of Retina Australia” group as such groups may not be established in every area.

FINAL COMMENTS

I am extremely optimistic that during the next twelve to eighteen months we will be able to establish solid foundations for the national operations of Retina Australia. I also believe that in the same timeframe, treatments and cures for some forms of inherited retinal diseases may become a reality.

Leighton Boyd
Chairman
Retina Australia



Stay up to date with the very latest information, including research, events and notice of the Retina Australia website launch, by ‘Liking’ the **Retina Australia** Facebook page.



CLEAR VISION RESEARCH AND RETINA AUSTRALIA FIGHTING TO PREVENT BLINDNESS



Recently, Clear Vision Research Laboratories at The Australian National University (ANU), The John Curtin School of Medical Research and The ANU Medical School, were delighted to host Robin Poke (President) and Jan James (Secretary) of Retina Australia (ACT). Dr Riccardo Natoli (Head of Clear Vision Research) and Dr Nilisha Fernando (Post-Doctoral Researcher, Clear Vision Research) took the opportunity to thank Retina Australia, for supporting their work into the treatment of retinal degenerations.

ANU has a long tradition of breakthrough Neuroscience research, starting in the 1950s with Sir John Eccles, who was awarded the Nobel Prize in Medicine in 1963 for his work in deciphering basic processes that cause electrical impulses, which control nerves and muscular movement. The Clear Vision Research Laboratories is continuing this tradition of research excellence and is at the forefront of research into the mechanisms of retinal degenerations. The group's position across the ANU Medical School and medical research centre, gives them a unique opportunity to bridge basic and translational research, enabling expedited 'bench to bedside' innovation. This has enabled the establishment of a number of commercial partners, a prolific publication rate and patents in the field of vision research.

So why did Dr Natoli decide to devote his career to studying the eye? “Well it’s the sense most people immediately think of when you ask them which one they couldn’t live without,” he said. “Also, when I was a student, I read a wonderful Oliver Sacks book called ‘The Man Who Mistook His Wife for a Hat.’ The stories of vision patients really stuck with me and I wanted to discover more about how the retina works and understand what happens when things go wrong. What started as an interest, has developed into a passion and now I have the opportunity to try and help everyone enjoy a visual life.”

The work conducted by Clear Vision Research is focused on looking at the role that inflammation plays in retinal degenerations. Work funded directly by Retina Australia is allowing Dr Natoli’s team to explore the molecular signature of retinal inflammatory cells, resident microglia and recruited macrophages, with a specific focus on microRNA (miRNA). These small molecules are known to be the ‘master regulators of gene expression’, and although highly abundant in the retina their role in retinal degeneration are largely unknown. This innovative team of researchers at the ANU are exploring if these miRNA can be used to slow down the ageing process in the retina by reprogramming the inflammatory cells. It is hoped their work will provide a better understanding of the mechanisms of inflammatory cell dysfunction in retinal disease, and identify possible therapeutic interventions for many retinal degenerations, including the currently incurable dry form of Age-Related Macular Degeneration, Retinitis Pigmentosa and Diabetic Retinopathy.

For more information on this research, please visit www.clearvisionresearch.com

PRESS RELEASE SNIPPET

ProQR Therapeutics N.V., a company in the Netherlands dedicated to changing lives through the creation of transformative RNA (ribonucleic acid) medicines for the treatment of severe genetic rare diseases, has announced the signing of an agreement with Ionis Pharmaceuticals to license QR-1123 (formerly “IONIS-RHO-2.5Rx”), an RNA medicine for autosomal dominant retinitis pigmentosa (adRP) caused by the P23H mutation in the rhodopsin (*RHO*) gene.

HUMAN RETINAS GROWN IN A DISH EXPLAIN HOW COLOUR VISION DEVELOPS

Date: October 11, 2018

Source: Johns Hopkins University

Summary: Biologists grew human retina tissue from scratch to determine how cells that allow people to see in colour are made.

Biologists at Johns Hopkins University grew human retinas from scratch to determine how cells that allow people to see in colour are made.

The work, set for publication in the journal *Science*, lays the foundation to develop therapies for eye diseases such as colour blindness and macular degeneration. It also establishes lab-created "organoids" as a model to study human development on a cellular level.

"Everything we examine looks like a normal developing eye, just growing in a dish," said Robert Johnston, a developmental biologist at Johns Hopkins. "You have a model system that you can manipulate without studying humans directly."

Johnston's lab explores how a cell's fate is determined -- or what happens in the womb to turn a developing cell into a specific type of cell, an aspect of human biology that is largely unknown.

Here, he and his team focused on the cells that allow people to see blue, red and green -- the three cone photoreceptors in the human eye.

While most vision research is done on mice and fish, neither of those species has the dynamic daytime and colour vision of humans. So Johnston's team created the human eyes they needed -- with stem cells.

"Trichromatic colour vision delineates us from most other mammals," said lead author Kiara Eldred, a Johns Hopkins graduate student. "Our research is really trying to figure out what pathways these cells take to give us that special colour vision."

Over months, as the cells grew in the lab and became full-blown retinas, the team found the blue-detecting cells materialised first, followed by the red- and green-detecting ones. In both cases, they found the key to the molecular switch was the ebb and flow of thyroid hormone. Importantly, the level of this hormone wasn't controlled by the thyroid gland, which of course isn't in the dish, but entirely by the eye itself.

Understanding how the amount of thyroid hormone dictated whether the cells became blue or red and green, the team was able to manipulate the outcome, creating retinas that if they were part of a complete human eye, would only see blue, and ones that could only see green and red.

The finding that thyroid hormone is essential for creating red-green cones provides insight into why pre-term babies, who have lowered thyroid hormone levels as they are lacking the maternal supply, have a higher incidence of vision disorders.

"If we can answer what leads a cell to its terminal fate, we are closer to being able to restore colour vision for people who have damaged photoreceptors," Eldred said. "This is a really beautiful question, both visually and intellectually -- what is it that allows us to see colour?"

These findings are a first step for the lab. In the future they would like to use organoids to learn even more about colour vision and the mechanisms involved in the creation of other regions of the retina, such as the macula. Since macular degeneration is one of the leading causes of blindness in people, understanding how to grow a new macula could lead to clinical treatments.

"What's exciting about this is our work establishes human organoids as a model system to study mechanisms of human development," Johnston said. "What's really pushing the limit here is that these organoids take nine months to develop just like a human baby. So what we're really studying is foetal development."



MEDITERRANEAN DIET PREVENTS LEADING CAUSE OF BLINDNESS, STUDY SUGGESTS

Date: October 1, 2018

Source: American Academy of Ophthalmology

Research shows we can all eat our way to better eye health

Summary: Evidence is mounting that a poor diet plays an important role in the development of age-related macular degeneration (AMD), a leading cause of blindness in the United States.

Evidence is mounting that a poor diet plays an important role in the development of age-related macular degeneration (AMD), a leading cause of blindness in the United States. A large collaboration of researchers from the European Union investigating the connection between genes and lifestyle on the development of AMD has found that people who adhered to a Mediterranean diet cut their risk of late-stage AMD by 41 percent. This research expands on previous studies and suggests that such a diet is beneficial for everyone, whether you already have the disease or are at risk of developing it. The new research is now online in *Ophthalmology*, the journal of the American Academy of Ophthalmology.

A Mediterranean diet emphasises eating less meat and more fish, vegetables, fruits, legumes, unrefined grains, and olive oil. Previous research has linked it to a longer lifespan and a reduced incidence of heart disease and cognitive decline. But only a few studies have evaluated its impact on AMD. Some studies showed it can help with certain types of AMD, or only at different stages of the disease.

But combining this earlier research on AMD with the latest data, and a clear picture emerges. Diet has the potential to prevent a blinding disease.

AMD is a degenerative eye disease. It causes loss of central vision, which is crucial for simple everyday activities, such as the ability to see faces, drive, read, and write. It's a leading cause of vision loss among people age 50 and older, affecting 1.8 million Americans. By 2020, that number is expected to climb to nearly 3 million.

For this latest study, researchers analysed food-frequency questionnaires from nearly 5,000 people who participated in two previous investigations -- the Rotterdam Study, which evaluated disease risk in people age 55 and older, and the Alienor Study, which assessed the association between eye diseases and nutritional factors in people aged 73 and older. Patients in the Rotterdam study were examined and completed food questionnaires every five years over a 21-year period, while patients in the Alienor Study were seen every two years over a 4-year period. The researchers found that those who closely followed the diet were 41 percent less likely to develop AMD compared with those who did not follow the diet.

They also found that none of the individual components of a Mediterranean diet on their own -- fish, fruit, vegetables, etc. -- lowered the risk of AMD. Rather, it was the entire pattern of eating a nutrient-rich diet that significantly reduced the risk of late AMD.

"You are what you eat," said Emily Chew, M.D., a clinical spokesperson for the American Academy of Ophthalmology, who serves on an advisory board to the research group conducting the study. "I believe this is a public health issue on the same scale as smoking. Chronic diseases such as AMD, dementia, obesity, and diabetes, all have roots in poor dietary habits. It's time to take quitting a poor diet as seriously as quitting smoking."

There are two kinds of AMD -- dry and wet. The dry type affects about 80 to 90 percent of people with AMD. In dry AMD, small white or yellowish deposits, called drusen, form on the retina, causing it to deteriorate over time. In the wet form, blood vessels grow under the retina and leak. While there is an effective treatment available for the wet type, there is no treatment available for dry AMD.



Retina International is delighted to announce the launch of our IRD Educational Toolkit to improve understanding of Inherited Retinal Diseases.

Retina International is a global umbrella of patient-led charitable organisations and foundations concerned with finding cures for retinal degenerative conditions including rare and age-related forms. The organisation has been successful in advocating for promoting research and development in the retinal space by fostering mutual support among those affected, their families and those who provide their care. RI is a powerful voice for the global retina community and today we launch www.retina-ird.org

The toolkit is designed to be a central information hub bringing patients, their representatives, health care providers and policy makers the most up-to-date information on the various forms of Inherited Retinal Diseases.

Inherited retinal diseases (IRDs; also called “inherited retinal dystrophies or degenerations”) are a diverse group of rare eye diseases, characterised by the progressive loss of function or death of light sensitive cells in the retina, resulting in associated vision loss or blindness. The underlying cause of all IRDs is the presence of a mutation(s) in genes involved in development and normal function of photoreceptors or other retinal cells.

It has been estimated that IRDs affect approximately 1 in every 3000 persons and can affect people of all ages – they are a leading cause of vision loss in people of working age and a common cause of visual impairment in childhood.

Speaking at the launch of the Toolkit the President of Retina International, Christina Fasser, stated ‘Early diagnosis, and especially genetic diagnosis, is key to give all patients access to supports and treatments to improve their quality of life. Retina International recognises the need for reliable and up-to-date resources to inform, educate and empower patients. The recent approval of the first gene therapy for a specific type of IRD called LCA that is due to biallelic mutations in the *RPE65* gene gives rise to a growing demand for more information for those affected, their families and professionals alike.’

A global survey was developed to better understand the needs of patients and the groups that represent them in order to provide the most useful information. It highlights the need for a clearer description of the various genetic forms of IRDs and the impact of much discussed scientific discovery on affected individuals and those who support them. We would like to thank our member organisations who contributed to this important survey.

IRDs are a complex collection of rare retinal degenerations. Given the breadth of information available about the various different types of IRDs, we will first launch Phase I with an initial focus on LCA and Usher Syndrome, and then follow with other conditions in Phases II and III. The Toolkit has been supported by an unrestricted educational grant from Novartis.

The aim of the IRD Toolkit is to serve our community and so we welcome any feedback, comments or suggestions that you think would help to improve it. It is for your benefit. Please feel free to use any part of this Toolkit. Please contact sarah.mcloughlin@retina-international.org with your feedback.

We hope that this important toolkit will help you in your understanding of IRDs.



The Board, staff and volunteers
of Retina Australia
would like to
wish you a very Merry Christmas
and a happy New Year
full of optimism
and hope for the future.



THE GIFT OF LIFE

by Lyn Lepore, member Retina Australia (WA)

I am one of seven siblings. Myself and my two sisters, Caterina and Adriana, were born with an inherited retinal disease called Retinitis Pigmentosa (RP). Recently, over the past 18 months, the three of us were re-diagnosed with Leber's Congenital Amaurosis (LCA), which doesn't make our lives any different, just a new title to our eye condition. In addition to LCA, my sisters and I were also diagnosed back in 1995 with Chronic Nephritis (kidney disease). I had my kidney transplant on 6 December 2016. Adam, the son of my sister Anna, generously gave me the very precious gift of life by donating his kidney to me.

Being a Paralympic athlete in the past, having represented Australia in three European Championships, three World Championships and three Paralympic Games (from 1994 to 2004), meant I was very fit and active. My kidney specialist said that being very active in sport slowed down the progression of my kidney disease. Coming from a sporting background, once I had my transplant, I got back into physical activity to stay fit and to give my precious kidney the best chance of a long life. In 2017, I heard of the Transplant Games. I did some research and found that the World Transplant Games were going to be held in Spain in July 2017. I got very excited and wanted to go and compete in Spain. Much to my disappointment, I was advised that I couldn't compete in the World Transplant Games as I needed to wait 12 months after my transplant before I could compete in any Games.

Soon after my transplant, I became a member of Transplant Australia (WA) and found out that this year, 2018, the Australian Transplant Games were going to be held at the Gold Coast from 29 September to 6 October. So, I signed up for those Games and started training. I decided to compete in the 3km walk race, swimming and Petanque (Bocci), and set off finding out times I had to achieve to be competitive, and so on.

I attended the Australian Transplant Games (ATG) with my partner, Paul, and my sister, Anna. Along with the Australian competitors, there were teams from Thailand, New Zealand, USA and Germany. Competitors consisted of transplant recipients and supporters. My first event was the Petanque singles which was on the Sunday we arrived at the Gold Coast. We got off our flight from Perth at 6:15am, dropped our things off at our apartment, went next door to register for the ATG and then straight on a tram to Petanque. It rained most of that Sunday and it was quite cold. I played in a round robin and, to my surprise, won a silver medal. Being blind, I had my partner Paul beside me, lining me up to throw the boules, and another person standing behind the small cosh (jack) clapping, so I could judge the distance. Anna was sheltered under a tree and came out to take photos between the rain. I'm not sure about the Queensland saying, "Beautiful one day, perfect the next"! For the rest of our time at the Gold Coast, the weather wasn't too good, but the atmosphere was fantastic and motivating.

We had a few free days before my next competition which was swimming on the Thursday. There were a few formal events to attend in those three days - Welcome Night on Sunday of arrival; Donate Life Beach Walk Monday morning to promote organ and tissue donation; Official Opening Ceremony Wednesday morning; and the Beach Welcome at Surfers Paradise on Wednesday evening where all the States and International athletes paraded around Surfers Paradise.

On the Thursday, I competed in the 50m freestyle, 200m freestyle and the 100m freestyle. It was a great day out at the pool, which was the same place where the Commonwealth Games swimming was held earlier in the year. I managed to win a Gold in the 200m freestyle and Silver in the 100m freestyle which I didn't think I would have a chance in, so it was a fantastic surprise. Then on the Friday, I competed in the 3km walk race which was the event I trained for. My partner, Paul, was tethered to me as my sighted guide in the 3km walk race. There were 20 competitors overall, ranging in age from 30 years old to over 70. I came 2nd overall and won Gold in my age division. That really topped off my Games and, having Paul and Anna with me was so special and I couldn't have done it without them. On the Saturday night, the Games were topped off with a fantastic Gala dinner where awards were given out and we all danced the night away.



ATG Opening Street Party



Lyn with partner Paul and sister Anna



Lyn in first place on the podium with her fellow competitors after the 3 km walk race

The Games for me were very inspirational as all the competitors, recipients and supporters, had overcome so much in their lives and didn't let that slow them down. Everyone was simply enjoying being alive and getting out there and participating the best way they could. Now, my focus is on the World Transplant Games next year in Newcastle, England from 17 to 24 August 2019. So, it's back to training hard for me...

To finish off, I would like everyone to give serious thought to becoming an organ or tissue donor. It's a very simple and an easy way to make a huge difference in someone else's life as it is truly a "Gift of Life". If you haven't done so, go and register NOW at <https://donatelife.gov.au>

Don't wait!! And, please talk to your families about your decision.

SHARE YOUR STORY

Sharing your story could help others affected by Inherited Retinal Disease

Retina Australia is looking for volunteers to share their story of living with an IRD. The new look Retina Australia website will feature a selection of short stories from people directly affected by an IRD or who provide support to someone close to them such as a child, sibling or partner.

If you would like to tell your story or would like further information please email info@retinaaustralia.com.au.

TUNLEY GLOBE DIGITISATION PROJECT

Sources: www.slq.qld.gov.au, www.booksandpublishing.com.au, www.abc.net.au, blogs.slq.qld.gov.au

The State Library of Queensland (SLQ) has won an industry innovation award, presented by Victorian organisation VALA—Libraries, Technology and the Future, for its Tunley Braille Globe Project.

The project involved the creation of a 3D-printed replica of a fragile Braille globe of the world, originally designed for vision-impaired children and invented by Queenslander Richard Frank Tunley in the 1950s. The globe allows children to understand the place of our planet, the size and shape of the countries and oceans, and use Braille to help their way around it.

Richard Frank Tunley was known as the ‘Fairy Godfather of Blind Children’, and dedicated his life to improving outcomes for vision-impaired children and adults, producing Braille globes and maps.

The replica globe can be touched and experienced as originally intended, and is accompanied by open access resources including digital 3D models and 3D printable files.

The biennial VALA award, open to all libraries and information services in Australia, is presented to the service that has made the most innovative use of information and communication technologies to improve its service to customers. SLQ will speak about the winning project at a VALA event in Melbourne on 29 November 2018.

The project involved creating 3D models of the globe using scanning techniques and photogrammetry to capture the finite details of it. User testing at Braille House indicated that the Braille markings in the reproduction print were difficult to discern as the Braille on the original had been worn down. It was decided to enhance the Braille marks in the 3D printed version. This work was undertaken by an industrial designer to create even and legible Braille.



EVENTS IN YOUR STATE

South Australia

Luncheon

On the **3rd Tuesday of every month** at the Strathmore Hotel in North Terrace, members of RASA get together for lunch arriving between 12 noon and 12.30.



This event has been going on for many years and not only members attend but sometimes ex-staff members also. The group welcomes new members and encourages them to come regularly.

For further information, contact Chris Hicks on 0497 491 115.

Queensland

The New Year will see the Brisbane coffee morning group back at the Community Meeting Room, Brisbane City Library at the top of Queen Street, on the fourth Tuesday of the month, from 9:30-11ish, beginning on 22 January. It is a great opportunity for members and friends to get together. If you would like to join us, contact retinafriends@gmail.com, or phone Graeme Ferguson on (07) 3849 7752.



As well as morning teas, you may like to come along for an occasional outing. You won't find better company or better fish and chips than at Dougie's on the bayside at Sandgate where we met last month.

MORNING TEA

Retina Australia (Vic) would like to invite all members and friends to share in their regular Morning Teas. These social events have proven to be very popular as they provide a means to network with others. Hope to see you there.



NEXT DATE: Tuesday 12 February 2019 between 10:30 am & 12:00 noon

PLACE: Jenny Florence Meeting Room, 3rd Floor Ross House
247-251 Flinders Lane, Melbourne VIC

RSVP: 03 9650 5088 by Thursday 7 February 2019

NEW PUBLIC TRANSPORT APP

People with low vision or blindness will have better access to Victoria's public transport network following the installation of innovative navigational technology at six of Melbourne's major train interchanges. This comes in addition to Southern Cross Station, where the pilot program took place in 2017.

Public Transport Victoria (PTV) CEO Jeroen Weimar joined Guide Dogs Victoria (GDV) CEO Karen Hayes at Flinders Street Station on International White Cane Day to announce the installation of the beacon wayfinding technology at:

- | | | |
|---------------------|-------------|--------------|
| - Flinders Street | - Flagstaff | - Parliament |
| - Melbourne Central | - Richmond | - Footscray |

The beacons, located around the station concourses, send signals to the app BlindSquare which translates the signal into navigational content.

The app then communicates this information to the user, giving directions to food outlets, toilets and lifts or escalators.

For more information, visit www.ptv.vic.gov.au/getting-around/accessible-transport/

May such initiatives signal further improvements to transport accessibility for vision impaired citizens throughout the country.

Research Summary by Dr Cathy Civil



At last... the Bionic Eye (the Argus II) has been approved for treatment of RP. However, be warned that it won't be suitable for everyone with RP, and that the chosen ones (!) will have to put in a lot of work themselves to get the best out of their new eye.... But wow...this is just the beginning of a new era for IRDs.... We can expect more and better treatments to emerge over the next few years...



A recent improvement to the Argus II bionic eye means that it will now be able to scan in a similar way to the normal human eye. This means that the user won't have to move their head as much as in the older models, and their vision will be better.



There has been a suggestion in the past that valproate tablets might be useful in the treatment of RP. However, further investigation has sadly shown that the drug makes no significant difference after all. Valproate is usually used to treat epilepsy.



An implantable miniature telescope (yes!) has been developed to improve vision in individuals who have lost central vision. This has only been trialled in age related macular degeneration so far, but could be useful for those with central vision loss from IRDs in the future. The telescope magnifies objects in the central field, and focuses them on to healthy areas of retina. Clever eh?! It means that subjects can potentially recognise objects that they otherwise would not see.



Nanotechnology (really really tiny technology!) is being investigated as an alternative to using viruses for delivering drugs into the retina.



QR-110 gene therapy targets all of the >150 faulty rhodopsin gene mutations in autosomal dominant RP, as opposed to most gene therapies which are only able to target individual gene mutations. It uses a viral vector.

Three months into a trial using QR-110 for autosomal dominant RP (the most common type of RP), 60% of animal subjects have had improved vision without serious side effects. Their wandering eye movements also improved. Human trials are starting next year.....



“Luxturna” has been approved in the USA to treat the RPE65 type of RP, which when inherited from both parents, usually leads to blindness by young adulthood. The treatment involves a one-off injection of fully functioning RPE65 genes directly into the retina. So far, 41 patients have been treated and the majority have had a significant improvement in vision after one year. The most common side effects have been some redness of the eye, cataracts, and mild glaucoma. The company has to do a 15 year follow up for effectiveness and safety. It is very likely that it will be approved for use in the EU very shortly..... And we will hope for an early Australian approval...



The first Usher syndrome patient (USH2) has received an Argus II bionic eye, aged 53. He had hearing loss from birth, very poor visual fields and good light perception. He communicated through sign language. His interpreter explained all the information regarding the surgical procedure and assisted in the post op visual therapy. Sixteen months after surgery, the gentleman was able to communicate more fluently with sign language, and was able to identify letters with high contrast over 6 cm, and identify words of up to four letters.



Monthly eye injections are often used to treat macular degeneration. Well a tiny refillable ocular implant has been developed, no bigger than a grain of rice, which sits inside the eye and releases medication very slowly. The device is then topped up as necessary, which seems to be only every 6 months or so, which reduces the number of injections needed enormously. It has already had a successful phase 2 trial with the drug Ranibizumab in 243 patients in the USA. Even though this treatment has not been developed for an IRD, there is no reason why the same technique could not be used in the future for IRDs if a medication needs to be injected into the middle of the eye.

PLEASE MAKE A BEQUEST

Please make a Bequest to help us in the fight against blindness.

Retina Australia is a voluntary organisation that assists and supports people and their families affected by inherited retinal diseases. With the assistance of the Australian community, Retina Australia raises money to provide grants for scientific research into the causes of, prevention and cures for, inherited retinal diseases.

Leave a gift in your will.

Every bequest that Retina Australia receives is vital to maintaining and developing the life changing service we provide for others. Without these and other generous gifts from people like you, we would not be able to provide the essential support that vision impaired people require.

What is a Bequest?

A bequest is a gift through a will. Your gift, be it large or small, to Retina Australia can make a significant and lasting difference. With your generous bequest, Retina Australia's mission will ensure that we will assist those affected by vision loss through inherited retinal diseases while working towards the global eradication of such diseases.

Your Gift can be:

- a specific sum of money
- a percentage of your estate
- a specific asset/s of your estate, such as property, shares, art, jewellery
- the residual of your estate, the remains after bequests to family and friends
- contributions to a perpetual trust
- an insurance policy

Leave a Legacy.... Long after you have gone.

Remembering Retina Australia in your will is a way to ensure that your legacy carries on long after you have gone. The next time you update your will, your solicitor can help you to make a bequest.



Volunteers
Fighting Blindness
With Your Help, Hope is in Sight.



Retina Australia Contact Details:-

Enquiry Line – 1800 999 870

Office – (03) 9650 5088 between 9:30am & 3:00pm Tuesday or Thursday.

Email – info@retinaaustralia.com.au

Website - <http://www.retinaaustralia.com.au>

Facebook – Retina Australia@RetinaAustralia

Our Vision

We have a vision we want people to see.

Our Mission

We will assist those affected by vision loss through inherited retinal diseases while working towards the global eradication of such diseases.

Our Goals

To facilitate support to individuals, families and friends affected by inherited retinal diseases.

To be a credible and preferred source of information related to inherited retinal diseases.

To raise and distribute funds for research into the prevention, diagnosis, treatment and cure of inherited retinal diseases.



Retina Australia needs your support in fighting blindness. You can help by subscribing to our quarterly Retina Australia National News Newsletter, fundraising and or making a donation to Retina Australia or your local state RA Group.

Your donation enables Retina Australia to support the great work by Australian researchers; it also provides information and peer support within Australia for those 1 in 3000 affected by inherited retinal disease.

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