SEPTEMBER 2021 ISSUE 20

RETINA AUSTRALIA QUARTERLY

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Chairman's Report

A word from Leighton

Welcome to the spring edition of Retina Australia Quarterly 2021. I trust that you are coping with the various challenges that the coronavirus (COVID-19) has placed on you during the previous eighteen months irrespective of where you live. It certainly has been a difficult time for all Australians.

I would like to acknowledge the significant contribution of our staff, Jun, Sally and Faik, who have been required to work from their homes throughout all lockdown periods. This has not been easy, but through the use of technology, and regular communication, they have kept the organisation going.

As you may be aware, this year Retina Australia held its first 24-hour Matched Giving Day on Monday 21 June 2021 to raise money for research. Thank you for your support of this innovative fundraising campaign. As a result of the generous donations provided, over $78,000 was raised. This was an incredible achievement.

The involvement and engagement from the community through our social and digital media channels was also fantastic to witness, and many messages of support were received on the positive impact of the campaign. All funds raised will be utilised for research grants awarded to researchers whose project involves an investigation into inherited retinal diseases.

Retina Australia has continued its series of successful webinars featuring topics

aimed at providing information that would be of benefit to those living with inherited retinal disease.

Previous research grant recipients have also reported on their investigations and provided an overview of other projects, and clinical trials, directly related to inherited retinal diseases, that are being undertaken throughout the world.

The next webinar will be held in conjunction with the 37th Annual General Meeting (AGM) of Retina Australia on Saturday 9 October 2021. Information about this webinar and details of how you can join, will be circulated by email, social media or in print to all members.

The AGM will be held by Zoom video conference commencing at 1:30pm (AEDT). If members do not have computer access, it is possible to participate by phone. The agenda will include the presentation of the 2020-2021 Retina Australia Annual Report and the audited financial statements. An election of Directors will take place if required. Further details will be circulated by mid-September to members entitled to vote at the AGM. If you have questions about this process, please do not hesitate to contact the office.

Thank you to all members who have renewed their membership for this current financial year. If you still wish to pay this subscription, please contact the office on Tuesdays or Thursdays between the hours of 9:30am and 3:00pm.

Thank you for your continued membership and support,

Leighton Boyd
Chairman
Retina Australia

Free Webinar Series 2021

Clinical genetics services helping with genetic information, counselling and access to clinical therapy, trials and research in the IRDs.

Date: Saturday 9th October
Time: 2.00pm EST (1.30pm in SA, 12.30pm in NT, 1.00pm in QLD and 11.00am in WA), following the Annual General Meeting.

Genetic information is critical for access to clinical therapy, trials and research studies for patients and families with inherited retinal diseases. Professor Robyn Jamieson, Dr Alan Ma and Ms Laura Wedd from the Department of Clinical Genetics, Western Sydney Genetics Program, Sydney Children's Hospitals Network and Westmead Hospital, will speak about referral pathways and possible outcomes of genetic testing for patients and families with IRDs. The patient journey will be discussed, as it relates to the genetic information, research studies to clarify genetic variants, available gene therapy, clinical trials and novel pharmaceutical and genetic therapy approaches.

To participate in this free event, you can connect via the internet or using your phone, either mobile or landline. To reserve a place, visit the Retina Australia website at: https://www.retinaaustralia.com.au/about-us-2/webinars-2021/ or click the link below to register:

Register here.

If you need assistance with registration, or would like more information about how webinars work, simply send an email with your name and contact details to info@retinaaustralia.com.au, or phone our office on 03-9650 5088.

To see recordings of our previous webinars, visit the Retina Australia website at: https://www.retinaaustralia.com.au/about-us-2/webinars-2021/ or visit our YouTube channel at the link below, or visit YouTube and search for Retina Australia:

YouTube channel link

Congratulations Heather Mack

Queen's Birthday Honour for Retina Australia board member

Congratulations to Retina Australia Board member Associate Professor Heather Mack, who was made a Member of the Order of Australia for “significant service to ophthalmology, particularly to professional colleges” as part of the Queens Birthday Honours announced on 14 June 2021.

Heather is a recipient of a 2021 Retina Australia Research Grant, focussing on potential participant perspectives on ocular gene therapy in Australia. Our members may have taken part in her extensive survey that was circulated earlier this year.

Congratulations Heather, and thankyou for your wonderful contributions!

Research Award

Funding for stem cell research in NSW

As part of the University of NSW's successful Medical Research Future Fund 2020 Stem Cell Mission grants, Dr Anai Gonzalez Cordero has been awarded a grant of $498,419 for stem cell derived-retinal organoids to test genetic therapies.

Dr Anai Gonzalez Cordero was a recipient in the 2020 Retina Australia grants program and we look forward to hearing updates about the progress of her research.

Going for Gold

Blind surfer Matt Formston aiming for a gold medal at the 2028 Paralympics

Source: ABC North Coast, posted online
Date: Sunday 2 May, 2021

Matt Formston makes surfing look easy, despite the fact that he does it legally blind. The former Paralympic cyclist lost 95 per cent of his vision at age five when he was diagnosed with Macular Dystrophy. But the diagnosis didn't deter him from pursuing an incredibly active life.

One that would eventually lead to gold and silver in the 2014 and 2015 Para-cycling World Champions and a top spot representing Australia in the 2016 Paralympic Games in Rio.

Since then, Matt has turned his ambitions to surfing, notching up an impressive three consecutive titles at the ISA Para Surfing World Championships. He said the ultimate goal was to represent Australia in the green and gold at the 2028 Paralympics for surfing.

Sound, swell and sun — navigating waves in the dark

Matt described his vision as "big black dots in the centre" with extremely blurry peripheral vision. "A lot of people would know what tunnel vision is. Mine's basically the opposite of that," he said. "I've got nothing in the centre at all, and then the outside's really blurry."

That means when he's in the surf, he relies on sound and feel to navigate and pick the right wave. "As you go up and down, there's a period between each wave," he said. "When a bigger wave that you want to catch comes … you'll drop further down. Over hundreds and thousands of hours surfing I've learnt to feel that, and I know to paddle as it gets steeper."

Matt said he also uses the warmth of the sun on his skin to orientate himself in the surf, from north to south and east to west. He is also constantly listening to the sounds around him – from the splash of other surfers paddling in a particular direction to the crash of waves breaking on the shore.

"If I'm surfing a point break, I can actually hear when a bigger wave hits the rocks out from where I'm surfing," he said. "If it's going to be a good one, sometimes it makes a louder noise or a softer noise."

When he's paddled onto a wave, Matt said he feels the steepness and listens to the white water to know where he needs to be on the wave to do certain manoeuvres. "Floating across the water, I can feel the little ripples going chink, chink, chink across the bottom of my board," he said. And then, as I do a turn, I can feel my rail just slicing through the water. It's just being in absolute flow with mother nature. Apart from spending time with my kids and being with my family, it's the most amazing thing in my life."

Love of surf runs deep

For Matt, who grew up in Narrabeen on the northern beaches of Sydney, the ocean has always been a part of life, as far back as he can remember. His mum surfed in Narrabeen in the 1960s, towing her 9'6 timber board to the beach behind her bike at a time when there were few female surfers. His Dad and older brother would take him to the beach and push him onto waves on a bodyboard from about the age of five.

Matt said it wasn't always easy for his parents to let their child go in the surf or onto the sports field — but he's incredibly grateful they did. "They were very courageous, letting me do those things from the point of view that I could get hurt but also from the point of view that they were looked at as not being caring parents because they were putting me in harm's way," he said.

Matt said although sport was a big part of growing up, he never really owned the fact that he had a disability. "It wasn't until my late 20s that I decided I do have a disability and wanted to have a crack at the Paralympics," he said.
Matt said his cycling career began with a 1,200km single-bike ride from Sydney to Melbourne using echolocation.

Wheels to fins — a transition from elite cycling to surfing
Although Matt reached the highest levels of competitive para-cycling, he said surfing had always been his first love. "It's been the thing that I would have loved to have gone to the Paralympics for, and probably would have gone as a teenager," he said.

"But there was no competition for people with disabilities, certainly not in Australia and not globally until 2016, which was when I went to the Rio Paralympics for cycling. I jumped off the bike and now I'm surfing for Australia."
Matt has recently relocated to the Far North Coast of New South Wales and is training with surf coach Michael 'Cripsy' Crisp. "When I first saw Matt surf, it was just amazing how in-tune he was with the wave," he said.

Michael said he was working with Matt to master some big, vertical manoeuvres — with the aim of taking out Gold in the 2028 Paralympics.

"My job is to get Matt into the best wave possible," he said. "So, I'm Matt's eyes … but then Matt has to perform still and bring it all together on the wave."
During their training session, Michael calls Matt onto waves and gives him verbal feedback and direction.

"It's releasing Matt to do what he does best."

Remarkable new insights into the pathology of Usher syndrome

Source: Johannes Gutenberg Universitaet Mainz
Date: July 12, 2021

Human Usher syndrome (USH) is the most common form of hereditary deaf-blindness. Sufferers can be deaf from birth, suffer from balance disorders, and eventually lose their eyesight as the disease progresses. For some 25 years now, the research group led by Professor Uwe Wolfrum of the Institute of Molecular Physiology at Johannes Gutenberg University Mainz (JGU) has been conducting research into Usher syndrome.

Working in cooperation with the group headed up by Professor Reinhard Lührmann at the Max Planck Institute for Biophysical Chemistry in Göttingen, his team has now identified a novel pathomechanism leading to Usher syndrome. They have discovered that the Usher syndrome type 1G protein SANS plays a crucial role in regulating the splicing process. Furthermore, the researchers have been able to demonstrate that defects in the SANS protein can lead to errors in the splicing of genes related to the Usher syndrome, which may provoke the disease.

Further research on how the SANS protein contributes to the development of blindness needed

"We are aiming to elucidate the molecular basis that leads to the degeneration of the light-sensitive photoreceptor cells in the eye in cases of Usher syndrome," said Professor Uwe Wolfrum. For sufferers with USH, cochlear implants can be used to compensate for hearing loss. However, there are currently no existing treatments for the associated blindness. The current investigation is focusing on one of the Usher syndrome proteins, the USH1G protein, known as SANS. Previous research undertaken by Wolfrum's team established that SANS acts as a scaffold protein.

SANS has multiple domains to which other proteins can dock, thus ensuring correct cellular function.

Mutations in the USH1G/SANS gene lead to malfunctions of the auditory and vestibular hair cells in the inner ear and of the photoreceptor cells of the retina, which are responsible for the sensory defects experienced by Usher syndrome patients.

It remains unclear how SANS contributes to pathogenic processes in the eye. Encoded by the USH1G gene, the protein is expressed in the photoreceptors of the retina and glia cells. "So far, we had thought of SANS simply as a scaffold molecule that participates in transport processes in the cytoplasm associated with ciliary extensions," said Wolfrum. "But recently, Adem Yildirim in his PhD thesis conducted in the International PhD Program (IPP) in Mainz discovered that SANS interacts with splicing factors to regulate pre-mRNA splicing."

SANS regulates the splicing of pre-mRNA

Splicing is an important process in the path from the coding gene to the biosynthesis of proteins. What happens during splicing is that non-coding introns are removed from initially transcribed pre-mRNA or, in the case of alternative splicing, exons that are not required for the subsequent protein variant are excluded. The resulting mRNA is then used for protein biosynthesis. The splicing process is catalyzed in the nucleus by the spliceosome, a dynamic, highly complex molecular machine that is successively assembled during the splicing process from a number of subcomplexes of protein and RNA components.

"We were surprised by our finding that SANS is not only a component of the transport to cilia at the surface of the cell but also active in the nucleus and can modulate the splicing process there too," said Wolfrum, referring to their results published in Nucleic Acids Research. In the cell nucleus, SANS is responsible for transferring tri-snRNP complexes, or components of spliceosome subcomplexes, from the Cajal bodies, a kind of molecular assembly line, to the so-called nuclear speckles. In this compartment, tri-snRNP complexes bind to the spliceosome assembly to subsequently activate it. SANS is also likely to be involved in recycling the tri-snRNP components back to the Cajal bodies.

The absence of SANS and also pathogenic mutations of the USH1G/SANS gene prevent the spliceosome being correctly assembled and sequentially activated.

This, in turn, suppresses the correct splicing of other Usher syndrome-related genes, ultimately leading to their dysfunction and therefore to the development of the disorder. "Thus, we provide the first evidence that splicing dysregulation may participate in the pathophysiology of Usher syndrome," is how the authors sum up their results in their article. And Professor Uwe Wolfrum added: "In addition to the new findings relating to the splicing mechanism, we have also identified new aspects that we aim to investigate with regard to developing concepts for the treatment and therapy of the Usher syndrome in future."

People who are blind navigate better after echolocation training

Source: New Scientist online, Health.
Date: 2 June 2021.

People who are blind are able to better complete various practical and navigation tasks with the help of echolocation, new research suggests. Echolocation occurs when an animal emits a sound that bounces off objects in the environment, returning echoes that provide information about the surrounding space.

While the technique is well known in whales and bats, some people who are blind use click-based echolocation to judge spaces and improve their navigation skills.

Lore Thaler at Durham University in the UK and colleagues looked into the factors that determine how people learn this skill. Over the course of a 10-week training programme, the team investigated how level of vision and age affect the learning of click-based echolocation, and how learning this skill affects the daily life of people who are blind.

Blind and sighted participants aged between 21 and 79 took part in 20 two-to-three-hour training sessions over the study period. Blind participants also took part in a three-month follow-up survey assessing the effects of the training on their daily life.

The researchers found that people who are blind and those who are sighted

improved considerably on all measures, and in some cases performed comparably with expert echolocators at the end of the training.

In the follow-up survey, all participants who were blind reported improved mobility, and 83 per cent reported better independence and well-being. The results are published in the journal PLoS One.

The results suggest the ability to learn click-based echolocation isn't strongly limited by age or level of vision, the researchers say, and this has positive implications for the rehabilitation of people with vision loss or in the early stages of progressive vision loss.

"I cannot think of any other work with blind participants that has had such enthusiastic feedback," said Thaler. "People who took part in our study reported that the training in click-based echolocation had a positive effect on their mobility, independence and well-being, attesting that the improvements we observed in the lab transcended into positive life benefits outside the lab.

"We are very excited about this and feel that it would make sense to provide information and training in click-based echolocation to people who may still have good functional vision, but who are expected to lose vision later in life because of progressive degenerative eye conditions," said Thaler.

Click-based echolocation is currently not taught as part of mobility training and rehabilitation for people who are blind. Experts say there is a possibility that some people are reluctant to use it due to a perceived stigma around making the required clicks in social environments.

Despite this, the results indicate that people who use echolocation, and people new to echolocation, are confident about using it in social situations, the researchers say.

Journal reference: PLoS One, DOI: 10.1371/journal.pone.0252330

Organic, printable device could restore sight to the blind

'Artificial retina' created using a biomedical printing press

Source: https://www.sydney.edu.au/news-opinion/news
Date: 15th May, 2021

A Sydney engineer is developing a low-cost, 3-D printed electrical device that uses absorbed light to fire the neurons that transmit signals from the eyes to the brain, acting as an artificial retina for those who have lost this capacity.

Dr Matthew Griffith, from the Australian Centre for Microscopy & Microanalysis and the School of Aerospace, Mechanical and Mechatronic Engineering, has created an electrical device from multi-coloured carbon-based semiconductors – that uses absorbed light to fire the neurons that transmit signals from the eyes to the brain, acting as an artificial retina for those who have lost this capacity.

The retina is the thin layer of tissue that lines the back of the eye which functions to receive light, convert it into neural signals, and send these signals to the brain for processing.

"Worldwide, the number of people living with vision impairment is at least 2.2 billion. Our research aims to provide a biomedical solution to those experiencing blindness from retinitis pigmentosa and age-related macular degeneration (AMD), the second being one of the leading causes of blindness in the world," said Dr Griffith.

Dr Griffith hopes to ultimately apply this technology, a type of neural interface, to restore sensory function to those with spinal cord injuries, and to treat people with neurodegenerative diseases. A neural interface is a device that interacts with an individual's nervous system to record or stimulate activity.

"Among other functions, neurons are the body's signal conductors. A missing neuron link, which can be caused by, for example, a spinal cord injury, can cause severe problems. It can also be debilitating if neurons misfire – this can cause

blindness and deafness, as well as diseases like Parkinson's and epilepsy, for which there is no cure," he said. "Neural interfaces can bridge this neuronal divide, or, in the case of misfiring, re-program the neurons."

Dr Griffith's device can be printed using the same, low-cost method as newspaper printing, with a high-speed roll to roll press. "Similar technologies are being intensively developed, though our device differs in that it is made of carbon – the same building block as human cells," Dr Griffith said.

"Other devices tend to be rigid and usually made of silicon or metal, which can present problems integrating with the human body that is soft and flexible. Our organic device is designed with this issue in mind."

Dr Griffith has been awarded an NHMRC Ideas grant to continue work on the project together with colleagues from the University of Sydney and neurobiologists from the University of Newcastle.

How the Device will work

It is intended that the device will be printed onto soft and flexible surfaces from water-based inks that contain nerve growth factors and then inserted into a patient's retina by a surgeon.

Once the relevant neurons reconnect to it, the retina will regain lost functionality when stimulated with light. At this stage, Dr Griffith and his team have conducted experiments using neurons from the spinal cord and eyes of mice.

Early experiments examined the growth of mice neuronal cells onto the semiconductors in a petri dish, after which the electrical activity of the neurons was tested. “Not only did these cells survive – they grew and maintained neural functionality,” Dr Griffith said.

“The next step is to control where they grow by printing nanopatterns. This is so in future, we can direct them to grow into specific bodily locations, like a spinal cord or retina.”

How it differs to comparable, sight-restoring technology

Comparable technologies are attempting to replicate both the eye and the brain in an effort to restore sight. Yet, this method requires a more sophisticated approach.

“Patients do get some vision back, which is definitely life-changing for those without sight. However, it’s not what you or I would think of as high-fidelity vision. Current state-of-the-art produces large blurry shapes in black and white,” Dr Griffith said.

Another key difference is that Dr Griffith’s device does not require any electricity – it is powered internally by light from the outside world. “If successful, our device will help us progress towards solving one of the great scientific challenges of the 21st century; communicating with the human body’s sensory network. We hope to achieve this using nothing but light, which opens up some really exciting prospects for the future of bioelectronic technology.”

Dr Griffith's team includes researchers and PhD students from the University of Sydney and the University of Newcastle, who work at the nexus of research in physics, biology, and medicine across both universities. The teams are also supported by cutting edge infrastructure and technical support provided by the Australian National Fabrication Facility and Microscopy Australia.

“It’s really exciting having the opportunity to contribute to such a life changing technology, which our team hopes will restore sight and movement in people who have lost these functions", said Rafael Crovador, a PhD student from the University of Newcastle who is working alongside Dr Griffith on the project. “Regeneration of sensory neurons using fully organic devices holds astonishing promise for the future and I’m grateful for the opportunity to contribute towards this collaboration through the use of neuroscience expertise."

Kellogg's UK launches cereal boxes for blind and partially sighted

Source: https://www.standard.co.uk/news/uk
Date: 1st July, 2021

Kellogg's UK is to permanently add technology it believes is a world first to its cereal boxes to make them accessible to blind and partially sighted people. The new boxes will allow a smartphone to easily detect a unique on-pack code and play back labelling information to shoppers with sight loss. The information will include allergen details, that can often be in print that is difficult for people with sight difficulties to read.

The new technology, called NaviLens, includes high contrasting-coloured squares on a black background. Users do not need to know exactly where the code is located to scan it. It allows smartphones using the free NaviLens app to pick up the on-pack code from up to three metres distance.

The shopper can choose to have the ingredients, allergen and recycling information read aloud to them as well as reading it on their device using accessibility tools.

The technology is currently used across transport systems in the Spanish cities

of Barcelona, Madrid and Murcia to help visually impaired citizens better navigate their way around. The first accessible boxes of Special K will arrive on shelves in January 2022, with all the firm's cereal packaging to follow.

The idea followed Kellogg's meeting with children from St Vincent's, a specialist school in Liverpool for children with sensory impairment, in 2019, with the firm crediting the pupils for raising the issue. Kellogg's said it hoped other brands might also work towards making supermarkets more accessible for those with sight loss. It follows a successful UK trial last year in partnership with Co-op on Kellogg's Coco Pops boxes.

An evaluation of the pilot by charity Royal National Institute of Blind People (RNIB) found that 97% of participants agreed that they would like to see more of these accessibility features available on grocery packaging in the future.

Chris Silcock, head of Kellogg's UK, said: "Over two million people in the UK live with sight loss and are unable to simply read the information on our cereal boxes. "As a company focused on equity, diversity and inclusion we believe that everyone should be able to access important and useful information about the food that we sell. That's why, starting next year, we are adding new technology to all of our cereal boxes. I am proud that Kellogg's will be the first company in the world to use NaviLens on packaging.

"We know it's important that all packaging is accessible for the blind community to enable them to make shopping easier, so we will share our experience with other brands who want to learn more."

Marc Powell, strategic accessibility lead at RNIB, said: "This announcement from Kellogg's is a real game changer within the packaging world. It marks a significant step-change in how big brands can put accessibility at the forefront of design and packaging decisions and be a catalyst for change.

"Important information on packaging can often be in very small print, making it difficult or impossible for people with sight loss to read. "Changes like this can provide blind and partially sighted people with vital information for the very first time, giving us the same freedom, independence and choice as sighted customers. Designing packaging so that it works for everyone makes complete sense and we hope that other brands will follow Kellogg's lead in making packaging information more accessible."

Containers for Change Partnership

Western Australia this one's for you!

Containers for Change is a recycling scheme that lets you cash in eligible containers. Its aims are to:

- Reduce litter and landfill
- Increase recycling
- Create jobs
- Provide opportunities for social enterprise and benefits for community organisation

For every eligible container deposited, you will receive 10 cents to either keep or donate. You can make a donation using our scheme ID number C10409605 when you return your containers to your nearest refund point.

For more information, visit the Containers for Change website at: https://www.containersforchange.com.au/wa/

Membership 2021 - 2022

It's time to renew your membership

If you have not yet renewed your membership for 2021- 2022, please consider making this payment, as all the money received helps us to run our operations, so that we can provide services and information like this newsletter to you. If you receive your newsletter electronically, you can download a membership form here.

Please contact the Retina Australia office on 03-9650 5088 if you have any queries or you would like to complete this payment over the phone.

Retina International Youth Conference

The 2nd Annual Retina International Virtual Youth Conference was held on 12 - 13 August, and provided a fascinating insight from a variety of guests and speakers. Topics discussed included assistive technology, research advancements, career pathways, and much more.

You can view the conference in full via the link: https://www.youtube.com/watch?v=8lJFpLkRO6k

Play for Purpose Raffle Tickets

Entries closing Thursday 16th September

Purchase your raffle tickets today by visiting the Play for Purpose website at https://new.playforpurpose.com.au/causes and don't forget to choose Retina Australia as your charity. Tickets are only $10 each and there are thousands of prizes to be won, including a fantastic $250,000 first prize pack!

Please note that unfortunately tickets are not available to residents of WA.

Entertainment Membership

Take advantage of this great offer today!

Renew your membership today, and support research into IRDs - for every purchase, Retina Australia will receive 20% of the purchase price.

To subscribe, click here, or visit the Entertainment website at: www.entertainment.com.au and remember to select Retina Australia as your charity.

Hot off the Press

World Research Summary by Dr Catherine Civil

Hello again folks. Here is my latest, very brief and hopefully reasonably digestible summary of research which has been published over the past few months in reputable scientific journals. It is good to know that the research does not seem to have slowed down despite the world being so heavily distracted by COVID.
So look below to see what lovely snippets are coming through the pipeline for you……

- Who would have thought that passing tiny electric currents through the eye could perhaps help slow RP progression (and other IRDs?)… a pilot study has suggested this.. more research please…..

And for those who need eye injections..

- The Port delivery system (refillable eye implant) is looking good as a substitute for monthly eye injections, with refills of ranibizumab anti-VEGF only needed every 6 months instead of the usual monthly treatments in a phase 3 trial.

- Alternatively, and potentially even more exciting is the outcome of the phase 1 trial of Aflibercept. This is a gene therapy given as a one-off eye injection which effectively creates an anti VEGF biofactory in the eye. No more eye injections. Now THAT is something!

- OdySight is a home vision monitoring program for maculopathy. Tests and games on your home computer allow specialists to monitor your visual acuity from afar and call you in to give early injections as necessary. This is similar to a Swiss smart phone app version which was more automated and also had good results for highlighting those who needed early injections. These eye injections have been a godsend in those with retinal vascular leakage. 20% of those affected have been able to retain useful vision for their remaining lifetime whereas previously 80% would have been legally blind within 3 yrs. 80% cease treatment for one reason or another. Longer intervals between treatments should enable more people to benefit.

- A number of people with neovascular AMD notice visual hallucinations and occasionally these can be scary. This is Charles Bonnet Syndrome. You can be reassured that the hallucinations fade away after a few months.

Stem cells ….

- AMD as well as some IRDs are looking good for treatment with pluripotent stem cells. The necessary cells are lab grown and then transplanted into the eye. This treatment is on the verge of clinical trials. The somatic cell transplants weren't so successful.

And regarding diet and supplements….

- Curcumin/cumin is anti-inflammatory and anti-oxidative so it follows that it should be useful for some IRDs. Keep putting it in your cooking folks!

- And don't forget that fish and omega 3 fatty acids (nuts and seeds) are helpful too. Yum.

- And keep up your vitamin D too, which you can get from sunlight on the skin or from daily supplements available from the pharmacy.

And gene therapies….

- Gene testing has now found more than 270 different genes associated with retinal dystrophies and their syndromes; And around 70% of patients with IRDs have now had their relevant culprit genes identified. This has been a huge and continuing project by groups such as our very own AIRDR (Australian IRD register). Once your genes have been identified you may lucky enough to be invited to take part in upcoming clinical trials.

- Phase 4 trials of Raxone gene therapy for Leber's have shown significant benefits after 12 months which were still there after 24 months…… These Lebers trials have been ground breaking, but since they started, the progress in the art of gene therapy has been astonishing, meaning that more and better gene therapies will be coming.

So there is lots of food for thought for you all there. There is light at the end of the tunnel….. Till next time, Cathy.

Get in Touch

Volunteers fighting blindness

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
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- Facebook – https://www.facebook.com/RetinaAustralia/
- LinkedIn - https://au.linkedin.com/company/retinaaustralia

Retina Australia Staff:

- Faik Demir, Fundraising and Marketing Manager
- Sally Turnbull, Administrative Officer
- Junxia Xu, Finance Officer

Retina Australia Board Members – 2020/2021

- CHAIRMAN: Leighton Boyd
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- COMPANY SECRETARY: Rosemary Boyd
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