THE ACHIEVER

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INSIDE

SPRING NEWS

Retina Australia recently made a decision to move towards one national newsletter which will be distributed quarterly commencing in December 2016.

To this end, Victoria and Queensland have combined articles to produce this very special edition of "The Achiever", which will be distributed in both states.

We believe all articles will be of interest to our readers and look forward to providing an Australian-wide edition of the Retina Australia News in three months' time.

PP: 33 1088/00015

From the President - Leighton Boyd

2016 RETINA INTERNATIONAL CONGRESS

I was fortunate to be able to attend this Congress and the associated business meetings which took place from 7th to 10th July 2016 at the Taiwan International Convention Centre in Taipei. The venue was centrally located in the business district of Taipei very close to the Taipei 101 Tower, built in 2004. This tower is world renowned for its environmentally conscious design, and at a height of 508 metres was the tallest building in the world for 6 years. Prior to the Congress, Rosemary and I took a lift to the lookout on the 89th level, travelling up in 37 seconds. We walked to the 91st level to see the very impressive, uninterrupted, views of Taipei and the mountains surrounding the city.

It was also fortunate that the Congress and its associated meetings and social events were able to proceed as Super Typhoon Nepartak crossed Taiwan at midnight on Thursday 7 July with winds gusting up to 295 km per hour at the centre of the storm. The damage was mainly confined to the south-east of the island, 300 km from Taipei, and although we had a considerable amount of rain to contend with, it was nothing like the 6-8 metres of rain in a 24 hour period in the southern mountains. Because the airports were closed for at least 24 hours, some of the speakers and delegates were unable to attend, and the program had to be reshuffled, but otherwise the event ran very smoothly.

During the Congress, Taiwanese, Chinese and internationally renowned scientists gave an overview of the latest medical advances in retinal eye diseases. Sessions were dedicated to Retinitis Pigmentosa, Age-related Macular Degeneration, Stargardt Disease, and other inherited retinal diseases (IRDs). Information was also provided about Stem Cell Therapy, Gene Therapy, Retinal Implants, Optogenetic Therapy, Transcorneal Electrical Stimulation and Genetic Screening. As well, some of the clinical trials currently being conducted around the world, and the prospect for future trials, were discussed along with issues including advocacy and accessibility, living with an inherited retinal disease, and mental health and mutual support.

The 19th Retina International World Congress was officially opened by Ms Christina Fasser, the President of Retina International, Mr Chao-Ming (Nick) Lin, Chairman of Retinitis Pigmentosa Taiwan and Mr Kin Ping (KP) Tsang, Chairman of Retina Hong Kong. In her opening speech, Christina spoke about the challenges facing those with IRDs. She said she was looking forward to wonderful talks about the scientific progress and to realise that the dreams of forty years ago are now becoming a reality. Christina then went on to say that all those in Retina International have the same dream that there may be a treatment, or even a cure, developed for IRDs in the foreseeable

future. Consequently we have to work with governments to assist them to ensure that such treatments are available all over the world and that people are not disadvantaged because of their background, ethnicity, or capacity to pay. She said that we have to ensure that any treatment, or cure, found is a human right and we must make sure that no-one is disadvantaged in the progress going forward.

After the official opening of the Congress, Ms Avril Daly, CEO of Retina International, introduced the keynote speaker, Professor Elise Heon from Toronto, Canada, who provided a clinical overview of retinal degenerations. In her presentation, Professor Heon explained the structure of the retina, the tools used for diagnosis including the differences between phenotype and genotype, the significance of DNA testing, and the importance of counselling and management of persons with an IRD. She also spoke about some of the current research and associated clinical trials, and the considerations for future research with particular reference to the inclusion of the patient in the process to discuss their needs, expectations and awareness of each IRD.

Professor Heon completed her talk by stating that:

- retinal degeneration can be associated with other defective body parts including ears or kidneys and this adds to the difficulties in providing advice to patients,
- in 1990 there were only 2-3 genes known for RP and now there are in excess of 200 involved with 17 known genetic causes for Leber Congenital Amaurosis as well
- genetic testing is faster than it used to be, however sometimes it is still like looking for a needle in a haystack

In summing up, Professor Heon said, “The concepts have changed over the years and so we need to be open minded. We have found out so much yet still have a long way to go.”

Congress speakers included:

- Professor Eberhart Zrenner from the University of Tübingen, Germany, who gave an overview of Retinal Implants, explaining their journey from laboratories to clinical applications. Professor Zrenner also mentioned that he has been involved in IRD research for over 35 years and stated that it is a very exciting time to be involved.
- Dr Shuichi Yamamoto, of Chiba University Hospital, Japan, provided an update about the Unoprostone Clinical Trial where eye drops typically used to treat glaucoma are now being used to treat IRDs, with varying degrees of success.
- Professor Morten Moe, Oslo University Hospital and University of Oslo, Norway, spoke about Stem Cell and Restoration of Eyesight. Professor Moe stated that stem cell therapy, which involves the repair, restoration, and/or replacement of damaged tissue, holds great promise for the treatment of a wide range of IRDs. He explained the various types of stem cells and the complex strategies being used to utilise stem cells in the treatment of IRDs, as well as some of the challenges facing researchers in undertaking this work.
- Dr Daniel Chung, from Spark Therapeutics, USA, spoke about the recent clinical trials using gene therapy for individuals with an IRD from autosomal-recessive

RPE65 gene mutations, and mentioned the importance of developing outcomes for all gene therapy trials that are relevant to the patient's needs. Dr Chung also stated that Spark Therapeutics were now more focussed on including effects on daily living as a major factor in determining the success of any trial.

- Professor Takashi Fujikado, Osaka University Graduate School of Medicine, Japan, talked about the research he has led since 2009 involving a retinal prosthesis system through the use of STS (suprachoroidal transretinal stimulation). He spoke about the advances his team has made, particularly in the safety and functionality of the device, and of plans for the future which may involve working with the Australian Bionic Eye team.
- Dr Paul Bernstein, Moran Eye Centre, University of Utah, USA, presented information about the importance of diet, and of taking specific supplements in appropriate dosages, to ensure that persons with IRDs can maintain their level of vision. He recommended that people with IRDs should include lutein, zeaxanthin, and meso-zeaxanthin in their diet. He provided data from his research which indicated that by managing nutrition there was a reduced rate of AMD by 4% over five years.
- Dr Gerald Chader, University of Southern California, Dr Gregg Kokame, University of Hawaii School of Medicine, and Ms Frances Fulton, USA, all talked about the retinal implant "Argus II", describing differing aspects of its roll out which has now been given approval for human use under certain conditions. To date there have been 180 successful implants for RP patients who have regained some functional vision as a result. The device is now available in 18 centres across North America and Europe and there are plans to expand the distribution worldwide.
- Professor Stephen Lam, The Chinese University of Hong Kong, Mr Richard Yang, Reflection Biotechnologies, Hong Kong, and Dr Takeshi Iwata, National Institute of Sensory Organs, Tokyo Medical Centre, Japan, spoke about the work of IRD clinics and the importance of gathering information about genetics and other aspects of IRDs to assist researchers. All three mentioned the collaboration occurring across Asia with respect to finding the causes of degenerative retinal disease so that, in turn, treatments can be found.
- Professor Chang-Hao Yang, National Taiwan University Hospital, Dr Shih-Jen Chen and Dr Shih-Hwa Chiou, Taipei Veterans General Hospital, Taiwan, Dr Patricia Zilliox, Foundation Fighting Blindness Clinical Research Institute, USA, Dr Katarina Creese, Centre for Eye Research Australia, and Dr Juliana Salum, UNIFESP Federal University of São Paulo, Brazil, provided up-to-date information about the studies being undertaken for Age-related Macular Degeneration and Stargardt Disease. It was clear from these talks that although the research has led to some successes with the treatments developed to date, valuable lessons have been learned from the studies undertaken and several challenges remain for the future. Overall though, these researchers were confident that it will not be long before persons with either form of AMD, or Stargardt Disease, will be able to access treatments that will make a huge difference to their sight, and to their lives.

- Professor Eberhart Zrenner, University of Tübingen, Germany, Dr Helmut Sachs, University Teaching Hospital, Dresden, Germany, and Mr Peter Böhm, ARA-Tec

GmBH, Germany, explained the rationale for the implantation of, and the reality of living with, the retinal implant "Alpha". They indicated that this sub-retinal implant can restore very low or low vision in blind patients and that the distributors were investigating the expansion of the market of such devices across Europe.

- Associate Professor Francesco Testa, Second University of Naples, Italy, Professor Tomita Hiroshi, Iwate University, Japan, Professor Dominik Fischer, University of Tübingen, Germany, and Dr Serge Picaud, Institut de la Vision, France, have all devoted their time to gene therapy research for IRDs. They each provided updates on a variety of clinical trials and a promise for future treatments as results of these trials, which generally involve an injection directly into the eye, are proving to be extremely positive.
- Dr Stephen Lam, The Chinese University of Hong Kong, Dr Keng-Hung Lin, Taichung Veterans General Hospital, Taiwan, and Professor Zibin Jin, The Eye Hospital of Wenzhou Medical University, China, all spoke about the importance of Genetic Screening for Patients with an IRD and the relevance of inherited patterns for such diseases. Their talks clearly indicated the significance of the work of our own Australian Inherited Retinal Disease Registry and compounded my belief that we must continue to support this team as much as we possibly can.
- Professor Eberhart Zrenner, University of Tübingen, Germany, and Dr Guido Blaess, Okuvision GmbH, Germany, explained about Transcorneal Electrical Stimulation Therapy. This procedure has completed all trials successfully and Okuvision has rolled out the use of the OkuStim therapy in Germany, Switzerland, Austria, Italy, Greece and Turkey. To date reports have indicated that all participants in this therapy are pleased with the change in their vision as a result.

Presentations were also made by people from Hong Kong, China, Taiwan and Japan, who personally were affected by an inherited retinal disease. They spoke about the Internet and screen reading software, guide dogs, mental health and mutual support, depression and progression, and the social support being offered by organisations such as Retina Hong Kong and Retinitis Pigmentosa Taiwan. Collectively, they were all very positive speakers providing the strong message that if you have determination you can overcome the obstacle of your inherited retinal disease and succeed in whatever challenges that life brings.

Dr Gerald Chader from Los Angeles, California, led the plenary session for the Congress by drawing conclusions from the many and varied presentations that had been delivered in both the scientific and general sessions. He stated that he believed it was now possible to look positively at the promise of clinical trials, and that many researchers are closer to moving inherited retinal disease treatments from the laboratory bench to the patient bedside. Dr Chader briefly spoke about AMD and mentioned that Wet AMD can now be fairly well controlled through the use of drugs but for Dry AMD, antioxidants can slow the disease. However the six therapy areas being covered for IRD are now being considered as potentially applicable for Dry AMD as well.

Dr Chader mentioned that: we know more than half of the genetic mutations that cause IRDs; it is now believed that stem cells planted into the photoreceptor may replace the dying cells; Apoptosis does lead to cell death; some cells such as skin cells can be redeveloped into stem cells for the eye; significant progress is being made in the area of gene therapy, optogenetics, neuroprotection and the use of antioxidants; and there are huge advancements in the use of retinal implants, with two versions available commercially (Argus II & Alpha). However, it is still extremely important that you take your mother's advice and eat your vegetables!

Dr Chader briefly summarised some of the clinical trials being undertaken currently, which include:

- The Ocata study in Massachusetts involving Stargardt Disease and Dry AMD;
- Dr Henry Klassen's (USA) work in supplying new photoreceptors to save cone cells;
- The use of stem cells by a group at RIKEN in Japan for Wet AMD studies;
- The London Project to cure blindness;
- The California Project to cure blindness;
- Optogenetic studies in France and Germany;
- Neurotech trials using a Ciliary Neurotrophic Factor (CNTF) on RP and Dry AMD;
- The RetinaComplex trial, comprising antioxidants to slow the progression of IRDs
- A number of Gene Therapy trials, worldwide, which show great promise, as all aim to restore some visual function for persons with an IRD.

Dr Chader completed his presentation by saying that during the previous 25 years researchers have made tremendous progress. He also said that at the most recent meeting of the Retina International Scientific and Medical Advisory Board held at the Washington State Convention Centre, Seattle, all of the talks reported on clinical trials, with no time for any news on basic studies. As a consequence he was very excited by the prospect that in the not too distant future treatments may be available for all IRDs.

The Congress was officially closed by Christina Fasser, Nick Lin and KP Tsang, who thanked the various major contributors to the event, the 40 speakers who represented many institutions or organisations world-wide, and the 680 people from 24 different countries who attended the Congress. Finally, Fraser Alexander, member of the RI management committee, and immediate past-president of Retina New Zealand, officially invited everyone to travel to New Zealand for the next Retina International Congress which will be held between February 8 and 11, 2018 in Auckland.

In association with the Congress, the Retina International General Assembly was held on Thursday 7 July. This was a day-long business meeting for members of Retina International and I participated in this as a delegate of Retina Australia. Attendance included representatives from 19 full member organisations, plus Retina Chile as a "candidate member". Apologies were received from 6 member organisations. The business of the meeting comprised governance matters, operational details including work plans for the CEO and the Management Committee, financial reports, approval of memberships, and planning for

future events including the next two World Congresses in New Zealand and Iceland respectively.

The General Assembly also included an election for the President of Retina International and members of the Management Committee. Results of the election were:
President - Christina Fasser (Switzerland)
Members – Fraser Alexander (New Zealand), Abdullah Yusuf (Pakistan), Claudette Medefindt (South Africa), Caisa Ramshagen (Sweden), K.P. Tsang (Hong Kong), Michael Laengsfeld (Germany) & Kristin Einarsson (Iceland)

I also attended the Retina International Continuous Education Programme on Friday 8 July. This programme enables individuals and member organisations to share experiences every two years with colleagues who are all representatives of Retina International members. Presentations were grouped into two categories: Communication & Advocacy, and Research & Drug Development. It was particularly interesting to hear Dr Patricia Zilliox from USA present an overview of ongoing and future clinical trials for Inherited Retinal Disease, and Dr Rogério Vivaldi from Spark Therapeutics, USA, provide the industry perspective about clinical trials in gene therapy and market access. The common theme from the remainder of the program was that, in the main, Retina International members provide support for their members, raise money for research and disseminate information regarding IRDs to raise awareness in the general and medical communities. Avril Daly, CEO of Retina International, presented the new website which was uploaded for the duration of the Congress in order for feedback to be provided about its content and accessibility. It is anticipated that the revamped website will be officially launched during World Retina week, which is 19 – 26 September 2016.

If you are interested in reading a more detailed summary of my Congress notes, or those relating to the General Assembly or the Continuous Education Program, please contact Jun at the office on 03 9650 5088, and she will email them to you. If anyone is interested in finding out more about the work of Retina International and its member organisations, please visit the website www.retina-international.org

2016 RETINA AUSTRALIA (VIC) ANNUAL GENERAL MEETING

We recently sent a notice of meeting for our forthcoming Annual General Meeting to be held on Saturday 10 September at Ross House commencing at 1:30 pm. This event is always quite exciting because of the presentations given by our speakers who are always well versed in their knowledge of Australian, and world-wide research. This year will be no exception with Ms Lisa Kearns of the Centre for Eye Research Australia (CERA) and the Royal Victorian Eye and Ear Hospital. Lisa is an integral member of various research teams and works closely with Associate Professor Alex Hewitt at CERA and with Professor David Mackey, from the Lions Eye Institute in Perth.

Please make attending this event a priority so that you can hear the most up to date information about Lisa's work in genetics and the research being conducted at CERA, and world-wide. There will also be ample opportunity to ask questions and socialise with other members present. Afternoon tea will be provided.

At the AGM, we will also be electing the office bearers and members of the Board who will serve for the next twelve months. Board members must be financial members of the Association. Nominations must be made in writing, signed by two financial members as well as the nominated candidate, and lodged with the secretary at least 14 days prior to the AGM. The Board currently meets eight times a year. If you are interested in finding out more about what this role entails, please do not hesitate to phone me at any time on 0417 566 899.

MEMBERSHIP RENEWALS IN VICTORIA

Thank you very much to all members who have recently sent in your renewal form and subscription for the current financial year. This money pays for the running costs of our office including our rent, telephone, printing, postage and the salary of our office staff member who works ten hours per week. Without your annual payments we would not have an office, nor be able to continue to support you, or assist people who have been newly diagnosed with a retinal disease and need information and peer assistance desperately. Hence we are indebted to your quick response.

For those members who have not had the time to send back your renewal and subscription, it is not too late. If you have misplaced the form please phone the office on 03 9650 5088 and let Jun know and she can send another, or if you prefer she can complete the form whilst you are on the telephone and take your payment by credit card. Forms can also be sent by email if this is easier for you.

DONATIONS

Last financial year in response to our letters of request for a donation towards Australian research, we collected in excess of $70,000. We have also received regular donations in response to our Target 300 campaign, through Give Now on our website, and recently have been supported by donors participating in "Good2Give", a workplace giving scheme. As well, many members have made a donation in addition to their membership subscription. All of these donations are greatly appreciated and I would like to thank you all most sincerely for your contributions. As you know all donations in excess of $2.00 are tax deductible and receipts are issued, along with a letter of thanks, to all donors.

As mentioned in previous correspondence and editions of The Achiever, donations from our members and friends have enabled significant research breakthroughs through our support of Australian researchers. We have also been able to contribute funds to Retina Australia specifically for the Australian Inherited Retinal Disease Register and DNA Bank. Hopefully these donations, and those still to come, will contribute to finding another significant discovery, treatment or cure for inherited retinal diseases. Thank you once again.

FEATURE

Our Paralympian Swimmers

Jacob Templeton

Tasmania will have an Olympic swimmer for the first time in two decades in Rio after Jacob Templeton was named in the 2016 Paralympic squad. The 20-year-old, who was born in Devonport but is now based on the Sunshine Coast, qualified in his pet event the 400 m freestyle at the national titles in Adelaide.

However he will have a big program in Rio as he is also able to compete in the 50 m and 100 m freestyle events, the 100 m butterfly and 200 m individual medley.

It is the first time a Tasmanian born swimmer has made an Olympic team since Scott Goodman raced in Atlanta in 1996. South African Melissa Carlton, who moved to the state in 1990, won two gold, four silver and three bronze medals at the 1996 and 2000 Paralympic Games.

Templeton was born with Retinitis Pigmentosa — a degenerative disease of the eye — and swims in the S13 classification as a visually impaired athlete. The TIS scholarship athlete donned the national colours at the world championships last year but admitted the news he is headed to his first Olympics was still yet to sink in.

“It’s been a bit of a nervous week, I suppose. It still kind of hasn’t sunk in to be honest. Moving from Tassie about two and a half years ago, everything that has been put in has been towards this. It is very pleasing to have paid off. I’m absolutely stoked, I’m almost 21 now so PBs don’t come easy but I did a few PBs this week as well as make the team, that kind of shows I had to swim as fast as I ever have to make it so that is really pleasing.”

Coached by former Australian athlete, Olympic medallist and Olympic head coach Jan Cameron, Templeton made the final in the 400 m at the world championships and will spend the months leading into the Olympics striving to bring down his best time even further.

“Last year at worlds I made a final so if I could do that this year at Rio I would be stoked. And just to push myself up the rankings, I think I was seventh or eighth in the world last year in the 400 m free.”

Liam Bekric

Liam Bekric will be representing Australia as a swimmer in Rio at the Paralympics. Liam was diagnosed with retinitis pigmentosa at the age of 6. Liam started swimming lessons when he was three years old. His older brother swam at a club and Liam wanted to join so he could be the fastest and beat him.

He started competitive swimming in 2011 and had his breakthrough year in 2014. He competed at the Australian Open Championships for the first time in 2014 and in November that year won a bronze medal in the multi-class 50 m breaststroke at the Australian Short Course Championships. Liam was just 13 years old, the youngest competitor at the event, racing competitors 10 years his senior. He was just 0.1 of a second off getting silver. At the 2015 Australian Open Championships Liam made the final in the 50 m breaststroke finishing fifth and the 50 m butterfly finishing seventh. At the 2015 Australian Age Championships, Liam won gold in the 50 m and breaststroke – defending both his titles from 2014. He also took silver in the 50 m and 100 m butterfly, and bronze in the 200 m individual medley.

Before focusing on swimming, Liam used to play cricket, karate, basketball and soccer. He is a huge soccer fan and lists Lionel Messi among his heroes. In 2013 Liam slipped while playing soccer and fractured his wrist. The injury kept him out of the pool for a month before he got a waterproof cast and continued training. Liam has the nickname 'Aquaman' because of his love of comics. He is a Marvel enthusiast – collects comic books, posters and DVD sets. He also likes playing his Xbox in his free time.

In the future, Liam would like to be a school teacher. It is his goal to be the best in the world for 50 m, 100 m and 200 m breaststroke. He is an ambassador for Variety and the Royal Society for the Blind – Dark to Light walk.

"I can't see around on the sides, can't read in the distance and I can only see a little cylinder," Liam says. "It's really hard when you don't know where the wall is at the other end or not being able to see other swimmers coming from the sides. But you catch up on little tactics like counting your strokes so you know where the wall is, pretty much, with your eyes closed. My vision is slowly decreasing over time. Swimming was probably the easiest sport with no contact."

Unable to play ball sports because of his limited vision, he turned to swimming when he was nine. Liam's great-uncle and his father, Dragan, have the same condition. Dragan uses an identification cane.

Sources: Mercury 5 April 2016, Messenger 14 November 2014 and www.paralympics,org.au.

Additional Paralympian News - Athletics

Brazil's three-time Paralympic sprinting champion Terezinha Guilhermina (who has Retinitis Pigmentosa) unveiled her new guide on 18 April 2016 in Rio de Janeiro, Brazil, none other than Jamaica's six-time Olympic champion Usain Bolt!

Bolt was in the host city of this year's Olympic and Paralympic Games to promote the Mano a Mano Challenge at the Brazilian Jockey Club and, grinning all the way, joined with Guilhermina to take part in a 50m sprint.

"It was a dream come true," said Guilhermina, who won 100m and 200m gold at the London 2012 Games and 200m gold at the Beijing 2008 Games. "He was a little uncertain at the start, afraid that I might fall over or that he would run too fast. This shows how much respect events like this bring to Paralympic athletes.

"Running with him [Bolt] is a joy for any athlete. Bolt is a reference in the sport and I'm happy to have participated in this race. I fulfilled a dream."

Source: IPC Athletics website

RETINA QLD FRIENDSHIP GROUP

For a relaxed social get-together, and also a source of information and support when you need it; Come along on the fourth Tuesday of the month and enjoy some good company and often a guest speaker of interest. If you would like to receive a reminder phone call or email, contact Wayne at retinafriends@gmail.com or phone Graeme on 07 3849 7752. Coffee mornings are held in the Brisbane City Library community meeting room on the corner of George & Elizabeth Streets.

QUEENSLAND BLIND CRICKET

With summer almost here, it's time to dust off the pads and get involved in a fabulous summer of fun with Queensland blind cricket. If you want to join or just want to find out more about upcoming events please email us at Qldblindcricket@outlook.com

CONGRATULATIONS - Stella Haralampou

Stella has just completed 40 years with the Queensland Blind Association. The Board and staff of the Association have just celebrated this career milestone with a luncheon in her honour. Retina Australia, and especially our Queensland members, would like to congratulate Stella on her contribution to the blind and vision impaired community.

Eye researchers awarded top Australian research fellowships

Two researchers from the Centre for Eye Research Australia (CERA) received top honours from the National Health and Medical Research Council (NHMRC) at an event in Canberra in July.

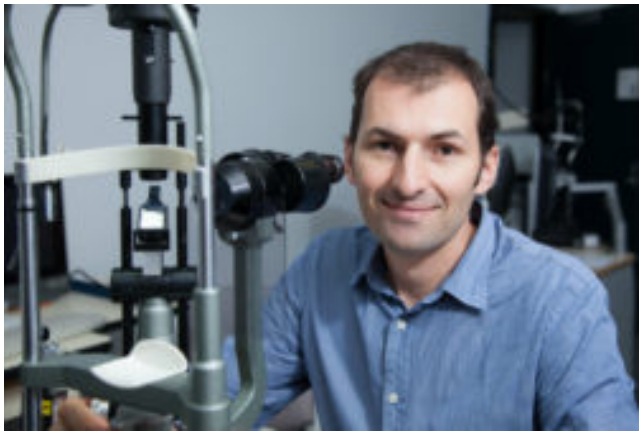
Deputy Director Professor Robyn Guymer was awarded a prestigious NHMRC Elizabeth Blackburn Fellowship to support her research into Age-related Macular Degeneration (AMD), whilst A/Prof Alex Hewitt has been recognised as the top-ranked NHMRC Practitioner Fellowship applicant. The Elizabeth Blackburn Fellowships are awarded annually to the highest ranked female applicant in each of the biomedical, clinical and public health pillars of the NHMRC's Research Fellowship scheme. Prof Guymer received the award for the Clinical Science and Medicine category.

Prof Robyn Guymer is a clinician-researcher focusing almost exclusively on AMD, the leading cause of vision loss and legal blindness in Australians over 50 years of age. Prof Guymer's research over the past two decades has looked at all aspects of this disease, from better understanding the pathological causes and risk factors of AMD, to defining the clinical signs and severity of the disease in a living eye, to testing of novel treatments for every stage of the disease.

"This fellowship will enable me to continue expanding the AMD research field by collaborating with basic scientists to address underlying mechanisms of the disease and then take our research findings into the clinic," said Prof Guymer.

Prof Guymer said she was honoured to receive the Elizabeth Blackburn Fellowship, which is specifically designed to support female scientists at the top of their field. "Like many women, I have to balance my family commitments with my career. I have to make choices every day – do I attend a networking event or a junior soccer match? We have come some way in trying to recognise and account for the impact of having children on a women's career, but it is also important to acknowledge the ongoing impact of family commitments on careers (mainly women's) as the children grow up."

Prof Guymer is on several advisory boards, is the clinical program leader and on the scientific leadership team of Bionic Vision Australia and is part of the Mactel consortium and Beckman AMD initiative in the USA. She is currently investigating new strategies for treating early stage disease with a nanosecond laser and is working to identify novel imaging and functional biomarkers and surrogate endpoints to allow efficacy of interventions to be determined.



A/Prof Alex Hewitt (CERA and the University of Tasmania) received a Research Excellence Award as the top ranked NHMRC Practitioner Fellowship applicant for his work on patient-specific stem cell lines and emerging gene-editing techniques. A/Prof Hewitt's research aims to understand the precise molecular mechanisms leading to blinding disease and develop novel therapies for these diseases.

"The overarching goal is to ensure that through targeted, evidence-based intervention, the next generation of people genetically predisposed to blinding ocular diseases have a dramatically different natural history to their forebears," said A/Prof Hewitt.

His main research interests lie in the molecular mechanisms of ocular disease, in particular the blinding disease glaucoma. He has been involved with work relating to the identification of genes and risk variants associated with primary open-angle glaucoma and myopia, as well as quantitative traits such as central corneal thickness, optic nerve size and the retinal microvascular circulation.

NHMRC Practitioner Fellowships are designed to support research that results in the translation of evidence into improved clinical practice and health policy, delivering improvements in health and healthcare to Australians.

Sources: *Vision 2020 Australia Sector News, 28 July 2016.*
www.cera.org.au, www.utas.edu.au

CONGRATULATIONS to both Robyn and Alex who have been friends and supporters of Retina Australia for many years. They have also contributed directly and indirectly to Australian research grants provided by Retina Australia. On behalf of everyone involved with Retina Australia I would like to wish them well for the future.

Call for Volunteers

Flinders University is conducting a study to explore the influence hereditary retinal diseases have on patient's overall **quality of life**. Therefore, volunteers are needed to **answer** a set of **simple questions** that ask about how your eye disease and its treatments are affecting you and your life.

What will be involved?
This study involves answering an **online survey** about how your eye disease and its treatment are affecting you and your life.

To participate or for further information please contact:
Mallika Prem Senthil - Optometry and Vision Science
Ph: 08 7221 8708 / 0450 755 338
Email: prem0013@flinders.edu.au

RESEARCH UPDATE

Pixium Vision announces CE market approval of IRIS®II, its first bionic vision system

CE mark certification enables market launch of Pixium Vision's innovative epi-retinal system equipped with a bio-inspired camera and a 150-electrode implant with a proprietary design intended to be explantable and upgradeable

Pixium Vision, a company developing innovative bionic vision systems that aim to allow patients who have lost their sight to lead more independent lives, has announced that it has been awarded CE mark for its IRIS®II bionic vision system. This 150-electrode epi-retinal implant features a design intended to be explantable and upgradeable. The IRIS®II system is now CE mark approved for people with vision loss from outer retinal degeneration.

Christina Fasser, President of Retina International, an umbrella association of 33 national societies, said: "*The progress in research with vision restoration of some visual perception is a reality, particularly with retinal prostheses. This research is addressing the growing patients' expectations and their hope to regain some sight. On behalf of our member organisations, we are delighted to welcome the new bionic vision system IRIS®II that may offer people suffering from retinitis pigmentosa a new treatment option with a design that is intended to be explantable and upgradeable."*

IRIS®II incorporates innovative and distinctive features:

- A bio-inspired camera intended to mimic the functioning of the human eye by continuously capturing the changes in a visual scene with its time independent pixels, and unlike an imaging sensor that takes a sequence of video frames with largely redundant information;

- An epi-retinal implant with 150 electrodes – almost three times the number of electrodes than previous version;

- An explantable design: the electrode array is secured on the retinal surface by a patented support system that is intended to allow for explantation or future replacements or upgrades.

The IRIS®II system is only available by medical prescription. Several leading ophthalmology centres in Europe are continuing to evaluate the system's long-term performance based on a pre-defined protocol. The company is now able to file for national reimbursements.

Khalid Ishaque, CEO of Pixium Vision said: "*The CE mark certification is a major step forward for Pixium Vision and for retinal dystrophy patients who have lost their sight. This recognition, by an independent expert body, validates the long-term multidisciplinary work that has resulted in market approval of the IRIS®II system. We will continue to develop our bionic vision systems with the aim to deliver improved visual perception and help retinal dystrophy patients lead more independent lives.*"

About the IRIS®II clinical study

Study title: "Compensation for Blindness with the Intelligent Retinal Implant System (IRIS V2) in Patients With Retinal Dystrophy.

The IRIS®II clinical trial is a multi-centric, open label, non-randomised prospective European study to assess safety and performance of the IRIS®II bionic vision system as treatment to compensate for blindness, providing a form of perception for blind persons and enabling them greater autonomy and quality of living. Up to 10 patients suffering from retinitis pigmentosa, Usher Syndrome, Cone-Rod dystrophy and choroideremia will be included and followed for a minimum of 18 months, with additional 18 months follow-up, subject to patient consent.

About CE mark

CE marking allows companies to legally market and distribute products within the European market and declares the product complies with all applicable European Directives and Regulations. For Active Implantable Medical Devices (AIMDs) like IRIS®II, CE Marking is granted by a Notified Body after review of design dossier and other information for conformity to the AIMD Directive. Following CE Marking, a product can be sold in the EEA (European Economic Area), and certain other countries.

About PRIMA

PRIMA is the second system developed by the company for patients with AMD. This tiny wireless photovoltaic sub-retinal implant has a modular structure and is currently in pre-clinical development. The company plans to launch clinical trials of PRIMA in Europe in 2016.

About Pixium Vision (www.pixium-vision.com)

Pixium Vision's mission is to create a world of bionic vision for those who have lost their sight enabling them to regain partial visual perception and greater autonomy. Pixium Vision's bionic vision systems are associated with a surgical intervention as well as a rehabilitation period. They aim to enable patients who have lost their sight to lead more independent lives.

Pixium Vision collaborates closely with academic and research partners spanning across the prestigious Vision research institutions including the Institut de la Vision in Paris, the Hansen Experimental Physics Laboratory at Stanford University, and Moorfields Eye Hospital in London.

Source: Pixium Vision, France, 25 July 25 2016.

Use it or Lose it: Visual Activity Regenerates Neural Connections Between Eye and Brain

NIH-funded mouse study is the first to show that visual stimulation helps re-wire the visual system and partially restores sight.

A study in mice funded by the National Institutes of Health (NIH) shows for the first time that high-contrast visual stimulation can help damaged retinal neurons regrow optic nerve fibres, otherwise known as retinal ganglion cell axons. In combination with chemically induced neural stimulation, axons grew further than in strategies tried previously. Treated mice partially regained visual function. The study also demonstrates that adult regenerated central nervous system (CNS) axons are capable of navigating to correct targets in the brain. The research was funded through the National Eye Institute (NEI), a part of NIH.

“Reconnecting neurons in the visual system is one of the biggest challenges to developing regenerative therapies for blinding eye diseases like glaucoma,” said NEI Director Paul A. Sieving, M.D., Ph.D. “This research shows that mammals have a greater capacity for central nervous system regeneration than previously known.” The optic nerve is the eye’s data cable, carrying visual information from the light-sensing neurons of the retina to the brain. Like a bundle of wires, it consists of about a million axons that each extend from an individual retinal ganglion cell. A variety of optic neuropathies, such as glaucoma, cause vision loss when they destroy or damage these axons. In adults, retinal ganglion cell axons fail to regrow on their own, which is why vision loss from optic neuropathies is usually permanent.

The researchers induced optic nerve damage in mice using forceps to crush the optic nerve of one eye just behind the eyeball. The mice were then placed in a chamber several hours a day for three weeks where they viewed high-contrast images — essentially changing patterns of black lines. The mice had modest but significant axonal regrowth compared to control mice that did not receive the high-contrast visual stimulation.

Prior work by the scientists showed that increasing activity of protein called mTOR promoted optic nerve regeneration. And so they wondered if combining visual stimulation with increased mTOR activity might have a synergistic effect. Two weeks prior to nerve crush, the scientists used gene therapy to cause the retinal ganglion cells to overexpress mTOR. Optic nerve crush was performed and mice were exposed to high-contrast visual stimulation daily. After three weeks, the scientists saw more extensive regeneration, with axons growing through the optic nerve as far as the optic chiasm, a distance from the eye of about 6 millimetres. Encouraged by these results, the researchers again increased mTOR activity but then forced mice to use the treated eye during visual stimulation by suturing shut the good eye. This combined approach of increasing mTOR activity with intense visual stimulation promoted regeneration down the full length of the optic nerve and into various visual centres of the brain.

“We saw the most remarkable growth when we closed the good eye, forcing the mice to look through the injured eye,” said Andrew Huberman, Ph.D., Associate Professor, Stanford University School of Medicine’s Department of Neurobiology, and lead author of the report, published online in Nature Neuroscience. In three weeks, the axons grew as much as 12 millimetres, a rate about 500 times faster than untreated CNS axons. The regenerating axons also navigated to the correct brain regions, a finding that Huberman said sheds light on a pivotal question in regenerative medicine: “If a nerve cell can regenerate, does it wander or does it recapitulate its developmental program and find its way back to the correct brain areas?”

Using transgenic mouse lines designed to express fluorescent proteins only in specific retinal ganglion cell subtypes (about 30 exist), the investigators traced where regenerating axons went. “The two types of retinal ganglion cells that we looked at — α-cells and melanopsin cells — seemed fully capable of navigating back to correct locations in the brain, plugging in and forming synapses,” said Huberman. “And just as interesting, they didn’t go to the wrong places.” Fluorescent axons appeared in brain regions where α-cells and melanopsin cells would be expected but were absent in other regions.

Visual function was partially restored in animals that received visual/mTOR combination therapy. The investigators used four tests to assess four types of visual perception: ability to track moving objects, pupillary reflex, depth perception, and ability to detect an overhead predator — a stimulus that normally causes mice to freeze or flee for cover. Mice treated with combination therapy performed significantly better than untreated mice in two of the four tests.

“This study’s striking finding that activity promotes nerve regrowth holds great promise for therapies aimed at degenerative retinal diseases,” noted Thomas Greenwell, NEI program director for retinal neuroscience research. Greenwell said the research has great relevance to the NEI Audacious Goals Initiative (AGI), a sustained effort to develop regenerative medicine for retinal diseases.

For future therapies that preserve optic nerve axons, Huberman envisions the development of filters for virtual reality video games, television programs, or eyeglasses designed to deliver regeneration-inducing visual stimulation. A drawback of the optic nerve crush model is that it does not mimic typical blinding diseases or injuries. The investigators are therefore currently examining the effect of intense visual stimulation in a mouse glaucoma model. Going forward, they are homing in on the specific qualities of visual stimulation that drive retinal regeneration.

This research was funded by NIH grant EY026100 and the Glaucoma Research Foundation. The NEI AGI is an effort to push the boundaries of vision science. By facilitating cross-disciplinary research, the AGI is tackling the most devastating and difficult-to-treat eye diseases.

Source: *nei.mih.gov, 11 July 2016.*

FACEBOOK'S BLIND ENGINEER

One billion people check their Facebook feeds every day, mindlessly scrolling through texts and photos to keep up with friends and family. Matt King joined Facebook in June as the company's first blind engineer to make sure millions of visually impaired Internet users around the world are not handicapped in their personal relationships simply because they can't do the same. Scrolling through the Facebook timeline has been a frustrating exercise using screen reading technology which simply goes quiet when reaching an image. Using artificial intelligence to identify broad but crucial elements of a photograph, the mechanical voice describes "may contain sky, tree and outdoor" – a vast improvement on silence.

More than many others tackling this problem, it is deeply, deeply personal for King. He wants to be able to work and live online and offline just as well as anyone else. Better in fact, according to interviews with friends, co-workers and King himself.

King has pushed himself physically to set racing records as a bicyclist. He has put in the hours to study how to play the pipe organ. He designed and built a house for his family. And he has worked as an engineer at some of the biggest and most revered technology companies around.

"He wants what you and I all want," says Rich Schwerdtfeger, CTO of Accessibility at IBM and a former colleague. "He wants to be able to go to work and not have to worry about the technology anymore."

To read the full story of Matt King's life and career go to Mashable Australia and search for 'Facebook's Blind Engineer'.

LINK VISION (Formerly Aid for the Blind) provides subsidised accommodation and computer training for people who are vision impaired. Their major fundraiser will be held on Friday, 9th September in King George Square in Brisbane. The annual Fashion Show and Sale showcases fashion from Bridal Gowns to bikinis from their op shops around Brisbane. To get the best bargains you should be there at 12 noon.

Question Time
With Rosalie O'Neil

Low vision doesn't stop anyone or anything.
Swimming at the Isle of Pines,
from a cruise ship.

1. What's your earliest memory?
Catching the train with my Mum from the station at Cannington into the city (Perth).

2. What's your idea of a good time?
Being around people who are able to talk, laugh and share.

3.What's your ideal holiday destination?
New York. So much to see, feel and do in a cosmopolitan city. I was there in 2012 and 5 days was not long enough.

4. Who inspires you?
People who are willing to explore their passions and share what they find.

5. What makes you angry?
People being selfish which results in others being harmed.

6.If you could change one thing about the world, what would it be?
That terrorism is something that no-one needs to worry about.

7. What's the hardest thing you've ever done?
Accept that I have osteoarthritis and central vision loss. In 2012 I was diagnosed that I would be in a wheelchair within 5 years, if I didn't get my knees and hips replaced. When I needed to be able to drive to maintain independence, I couldn't because my Stargardt disease had progressed to having to stop driving.

8. What's the best thing you've ever done?
My two daughters who keep me motivated, inspired and grounded. I'm a grandmother for the second time in September.

9. What do you like about Retina Australia (Vic)?
That they exist and I'm not by myself in this journey.

10. What's the most important thing you've learnt about life?
That I have a responsibility to love and look after myself. When I can do that, love and happiness will be around me.

LAST WORD

Out of clutter, find simplicity.
From discord, find harmony.
In the middle of difficulty
lies opportunity.

ALBERT EINSTEIN, 1879 - 1955

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To advise change of address or name, please enter your new particulars below. Then mail the whole of this page, which includes your existing particulars, to:

Retina Australia (Vic) Inc., 247–251 Flinders Lane, MELBOURNE VIC 3000, Fax to 03 9639 0979 or email to support@retinavic.org.au

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Melbourne, VIC 3000
www.retinavic.org.au

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