



THE **ACHIEVER**

Retina Australia Victoria
Registration # A0002991W

SUMMER EDITION

DECEMBER 2015

ROSS HOUSE, 4TH FLOOR
MELBOURNE VIC 3000

247 - 251 FLINDERS LANE
PHONE (03)9650 5088
FAX (03) 9639 0979

Email: support@retinavic.org.au

Web site: www.retinavic.org.au

INSIDE

FROM THE PRESIDENT	2
NATIONAL CONGRESS	5
FEATURES:	
BLINDNESS HASN'T STOPPED	
FATHER OF SEVEN	7
A LOSS OF SIGHT, A LOVE	
FOR LIFE	8
RESEARCH UPDATE:	
FDA CLEARANCE FOR RETROSENSE	
LEAD GENE THERAPY CANDIDATE	9
PSYCHOLOGICAL DISTRESS IN	
CAREGIVERS TO AMD SUFFERERS	10
ROLE OF EST IN OPHTHALMIC	
DISEASES	11
CONVERTING RODS INTO CONES	
IN A MODEL OF RP	12
HOLIDAY OPPORTUNITIES	14
QUESTION TIME	16
FUNNY CHRISTMAS QUOTES	17
LAST WORD	17

SUPER SUMMER EDITION

- Report on Retina Australia National Congress
- Retina (Vic), Retina Australia and Retina International news
- Features and latest research
- Holiday opportunities



*Merry Christmas
& Best Wishes
for 2016!*

PP: 33 1088/00015

From the President - Leighton Boyd

It is hard to believe that I am writing the fourth president's article for the year and that Christmas is just around the corner. This year has been particularly busy for the staff and volunteers at Retina Australia (Vic) who have continued to support our members, and potential members, through: peer support; participation in Telelinks; providing information; the regular distribution of this newsletter; and raising funds for research as well as plan for, and host, the Retina Australia National Congress – Global Eyes 2015.

I am extremely proud to report that the Congress was a resounding success. Evaluation forms were received from 47% of the delegates and our analysis of this data indicated that 92% of the delegates rated the Congress as excellent or very good, overall. A complete Congress report is included in this edition of The Achiever but I would like to thank most sincerely Mary-Anne Carmody, Rick Clarke, Rosemary Boyd and Jun Xu for their invaluable contribution towards ensuring that the Congress was well organised and ran smoothly.

RETINA AUSTRALIA (VIC) AWARD

This annual award was introduced in 2013 to recognise the significant contribution of individual members, and others, to the work of Retina Australia (Vic). At this year's AGM, Board Member Mary-Anne Carmody presented a Certificate of Appreciation to Rose Petrotta for her services and contribution. Rose has very capably coordinated the fortnightly Telelink for over six years and has contributed as a member and volunteer of Retina Australia (Vic) for twenty years.



Congratulations Rose. Thank you for your many years of support and dedication to the work of Retina Australia (Vic).

2015 ANNUAL GENERAL MEETING

This year we invited two of our members, Ross Anderson and David Simmonds to be our guest speakers. It was most interesting to hear about their personal stories.

Ross spoke about his Doctorate of Philosophy study which involves working with young people, who are blind or vision impaired, in order to understand issues of wellbeing. He mentioned that these young people were generally well looked after by the Vision Rehabilitation Services in respect to Orientation and Mobility, IT support and even career training, but that no support service provided assistance around finding "balance" in life. He also spoke about how it is extremely important to discuss with young vision impaired people what it is that they need, and particularly what it is like to live with vision impairment, so that appropriate services can be provided. He is

hopeful that his studies will eventually lead to young vision impaired people having a greater choice and control in their lives and that more emphasis will be placed on their general health and wellbeing by the support agencies as a result.

David spoke about his own “vision loss story” which involved training as an electrician and driving classic cars and motor cycles before changing direction to a career in finance and using public transport as his eyesight deteriorated. David mentioned that he had travelled a lot throughout Australia with his work and that now, in his new role at Guide Dogs Victoria (GDV), he has the opportunity of travelling throughout Victoria as he talks to community groups and to persons who are blind or vision impaired about GDV and the services they offer. David then explained about the advocacy component of his work and the importance of working with the Taxi Services Commission and Public Transport Victoria so that together they can ensure that persons travelling with a Dog Guide are not discriminated against. David then answered some questions from members and provided some hints about lodging complaints against restaurants that refused entry to dog guides, and also for using a mobile phone to book taxis so that if there is a problem you have a record of the details of the booking and can easily lodge a well-informed complaint against the relevant driver.

At the AGM, the office bearers and members of the Board who will serve for the next twelve months were elected. They are:

President:	Leighton Boyd
Vice President:	Rick Clarke
Secretary:	Rosemary Boyd
Treasurer:	Mary-Anne Carmody
Board Member:	Ross Anderson
Board Member:	Sarah Ceravolo
Board Member:	David Simmonds
Board Member:	Janice Remedios

This is the first time for many years that we have a full complement of Board members. I would like to extend a special welcome to Ross, Sarah, David and Janice who have joined the Board for the first time.

If any member would like a copy of the 2014-2015 Annual Report, which was distributed at the AGM, please contact the office.

RETINA INTERNATIONAL CONGRESS 2016

This event will be held on 9 & 10 July at the Taipei International Convention Centre in Taiwan. Information about this Congress is available on the website <http://riwc2016.org> If you are interested in attending this event which promises to be of significant value and provide updates of inherited retinal disease research throughout the world, you should check the website for the latest information. I understand that the website is being constantly updated so check regularly so you don't miss the early bird specials.

Don't miss out! Put the dates in your diaries, and plan to be in Taiwan at this time.

RETINA AUSTRALIA RESEARCH GRANTS 2016

Congratulations to Dr Livia Carvalho from the University of WA, and Dr Matthew Rutar from the Australian National University who were awarded grants for \$40,000 and \$39,901 respectively to undertake research in 2016. The Australian Inherited Retinal Disease Register & DNA Bank will be provided with \$110,000 in order to employ a senior research scientist to continue their work with samples gathered from persons affected by inherited retinal disease.

Dr Carvalho will study *“Cone photoreceptor development and cell death mechanisms during retinal degeneration in mouse models of Achromatopsia”* and Dr Rutar will consider *“The role of complement activation in retinal degeneration”*.

These grants are possible due to the pooling of funds raised from the donations of members and friends of Retina groups in all states and territories. Due to such generous donations, Retina Australia has been able to provide funds for research on an annual basis for almost thirty years.

On behalf of Retina Australia and all of the researchers who have benefitted over the years from these grants I would like to thank all donors for their generosity. It is certainly very much appreciated.

RETINA AUSTRALIA ANNUAL GENERAL MEETING 2015

This AGM was held in Melbourne on Monday 26 October 2015. The directors of Retina Australia are now as follows:

RA (ACT)	Jan James; John Barlow
RA (NSW)	Bruce Richards; Robert Craft
RA (Qld)	Anne Housego; Marg Veltheim
RA (SA)	Philippa Cooper (Treasurer); Orm Cooper
RA (Vic)	Leighton Boyd (President); Rosemary Boyd (Secretary)
RA (WA)	Cathy Civil; Jeremy D’Souza (Vice-President)
Individual Member	Graeme Banks

The former national president Graeme Banks, and each of the state presidents, presented their reports at the AGM, outlining what activities each organisation has been undertaking during the previous financial year. The audited national financial reports were also presented and accepted.

At the Board meeting immediately following the AGM, I was once again elected as President of Retina Australia, having been in this role a number of times during the 32 year history of the organisation. Graeme Banks did not seek re-election due to workload involved with his other voluntary commitments; however he will remain on the Board. I would like to thank Graeme for his significant contribution as the President of Retina Australia and wish him well for the future.

The Retina Australia Board is currently involved in a discussion of the future role of Retina Australia. Directors will hold a strategy meeting in Melbourne early next year to

consider how best to move forward in the charity environment where volunteers are becoming more scarce and social media and other forms of technology are having an increasing influence on the not-for-profit sector.

OFFICE CLOSURE

As is our usual practice, the office will be closed during the Christmas, New Year and January holiday period. This allows our office staff and volunteers to have a well-earned break and enjoy time with their families. This year, our last day in the office will be Thursday 17 December 2015 and we will reopen again on Tuesday 19 January 2016 at 9.30am. During this closure period, I can be contacted on 0417 566 899.

IN CONCLUSION

Thank you all very much for your continued support and assistance. I hope that you all have a wonderful Christmas and a happy New Year and are able to take the time to celebrate this special time with family and friends.



Retina Australia National Congress
GLOBAL EYES 2015
Melbourne | October 23rd - 25th

This event was held at the ibis Melbourne Hotel between 23rd and 25th October. It was officially opened by Frank McGuire MP who is the Victorian Parliamentary Secretary for Medical Research. Frank spoke about this newly created position and of his personal commitment to ensuring that government funds were found to support research in addition to the Premier's Awards for Health and Medical Research. Frank remained at the Congress to hear the keynote address and to meet and chat to delegates over morning tea.



Dr Gerald Chader, the Executive Director of the California Project to Cure Blindness from the University of Southern California, Los Angeles, USA provided the Keynote Address. His talk entitled *"Retinal Degeneration: Moving from Scientific Darkness to the Light of Clinical Trials"* provided a clear synopsis of how research into inherited retinal diseases has developed during the previous twenty-five years.

Dr Chader spoke about the developments in Genetics, Artificial Vision, Optogenetics, Neuroprotection, Antioxidants and Gene Therapy. He also explained about the number of clinical trials currently being undertaken and talked about some trials that he knew were being planned. Dr Chader was particularly excited about the developments in Gene Therapy which will restore some visual function and provided examples of the work of researchers including Dr Robin Ali in London and Professor Jean Bennett from

Philadelphia. In summary, Dr Chader stated that the “many years of hard work at the laboratory bench have led to many clinical trials that are testing meaningful and sight-saving therapies which will lead to new and improved treatments that will save and restore vision for patients with inherited retinal disease”.

The remainder of the program was divided up into sections as follows:

- (i) Bionics with presenters Professor Nigel Lovell, Dr Lauren Ayton, Associate Professor Nick Barnes, Dr Di Ashworth and Professor Arthur Lowery who discussed the Bionic Vision Australia retinal prosthesis trial and its future directions as well as the work of the Monash Vision Group and their Cortical Bionic Eye.
- (ii) Genes, Gene Therapy, Epigenetics and Genomics with presenters Associate Professor Alex Hewitt, Dr Livia Carvalho, Ms Lisa Kearns and Dr Tina Lamey who provided an overview of the genetics of retinal disease, the developments in retinal gene therapy and some facts about inherited retinal diseases in Australia.
- (iii) Stem Cells where information related to the barriers for clinical application of such therapy, modelling for retinal diseases, correcting mutations and the progress in stem cell science was provided by presenters Associate Professors Fred Chen, Megan Munsie, Alice Pebay and Dr Sandy Hung.
- (iv) Mechanisms of Retinal Disease which included presentations by Professor Erica Fletcher, Dr Matthew Rutar, Associate Professors Robyn Jamieson & John Grigg and Dr Marc Sarossy. Topics included: how the inner retina affects vision restoration; inflammation of the retina; pathways to therapy; advances in electrophysiology and ocular imaging; and detection of retinal ischemia.
- (v) Other related topics which included a report on the lived experiences of people with retinal diseases provided by Dr Mallika Prem Senthil; the development of a Low Vision Activities of Daily Living Tool explained by Dr Lauren Ayton; the current status of the Australian Inherited Retinal Disease Register and DNA Bank provided by Dr John De Roach and Ms Terri McLaren; and how Viagra impairs vision explained by Professor Michael Kalloniatis.

The Congress was attended by 168 delegates including 3 from New Zealand, 1 from Germany and 2 from the USA. As well as the researchers, ophthalmologists and optometrists in attendance there were over 120 people personally affected by inherited retinal disease. The 25 presenters came from research institutions across Australia. The two workshops on Technology and Strength, Balance and Positive Thinking were led by representatives from Vision Australia, Humanware, Pacific Vision and Qantum.

Highlights of the Congress were the keynote address by Dr Gerald Chader, the panel session wherein nine researchers fielded questions and provided advice about the “future of Bionics, Gene Therapy and Stem Cells, including information about clinical trials in Australia” and the Congress Dinner where delegates were entertained by Ms Betty Amsden AO who spoke about her life experiences. Given all the planning that took place over the previous eighteen months it was very pleasing to have such a successful event.

FEATURES

Blindness hasn't stopped father of seven, Grant Baker

Grant is a proud father of seven and an inspirational person. Not only is he a personal trainer at 52 years old, but he has also won two Kick Boxing world titles despite having very low vision. Grant has an eye disease called Retinitis Pigmentosa (RP) and he has a Seeing Eye Dog, called Fender, to help him get around independently.

When Grant was 16, he first started to notice problems with his eyesight. Due to his resourceful nature he was able to carry on with his failing vision doing most of the things his ambition was driving him toward.

He became a successful personal trainer, started a family and pursued a career in kick boxing, which resulted in two world kickboxing titles. "Back then they didn't test your visual field to compete in kickboxing."



Grant with Fender

After nearly two decades of living with an undiagnosed eye disease Grant was finally diagnosed with RP.

"My philosophy in life is to make do with what you've got. I didn't even think about it when I was diagnosed with RP. I just feel blessed to still have some vision," says Grant. In recent years Grant has become a motivational speaker and talks about overcoming life's challenges by telling his own story.

Grant has undertaken fundraising for charities. The Harcourts Foundation recently gave Grant \$5,000 to donate to a charity of his choice after he gave an inspirational talk at an event. On behalf of the Harcourts Foundation, Grant donated the \$5,000 to support Vision Australia's Accessible Information Library.

Grant has been a Vision Australia client for a year. In that time he has received a Seeing Eye Dog. Grant's four youngest children stay with him every weekend. Vision Australia Orientation and Mobility staff gave Grant advice on safe ways to cross the road when with his kids and also provided him with tips on daily living challenges, like how to pour hot drinks safely. "It's a great service," says Grant. "I want to do what I can to support and promote awareness of the organisation."

Source: *Vision Australia, 4 September 2015.*

A Loss of Sight, a Love for Life

For Allan Peterson, the world around him has long been dark, but he's working to brighten it for those like him. Diagnosed with retinitis pigmentosa soon after he joined North Dakota State's veterinary science faculty in 1977, Peterson lost his sight over 10 years. "My retina doesn't work and so I don't see," he said. "I don't see at all at this point. I've lost all my sight."

Despite his disability, he continues to serve the North Dakota State University (NDSU) campus and others living with disabilities through his work with various organisations. "I enjoy life. I enjoy a challenge," he said. "I've certainly been presented with one." Trained as a veterinarian, Peterson attended the University of Minnesota's School of Veterinary Medicine before his post-doctoral work in veterinary microbiology and pathology at NDSU. His advocacy work is just as extensive.



Peterson has served on various boards, including Handi-Wheels Transportation, a non-profit providing transportation to North Dakota Medicaid customers. He's also a long time board member of the North Dakota Association of the Blind, the American Council of the Blind and NDSU's Lutheran Centre. His numerous projects are all geared toward helping those living with disabilities or who have lost their sight like him. "I like to see achievement," Peterson said. "I like to see things happen, the cause of people with disabilities advanced."

Peterson found his independence following his loss of sight by finding new ways to interact in his environment. He learned how to use a cane to walk and a computer to communicate using speech. "I learned my way around campus without the advantage of sight," Peterson said. "I rely on my computer and rely on my cane and my other senses." He added he can get disoriented due to noise or construction and can get confused if someone tries to lend a helping hand.

"A lot of students don't know how they can help," Peterson said, adding with a laugh, "Often a student will open a door for me and I don't know it's open. They don't say anything and that can be a bit of a challenge." Peterson added he does appreciate people asking how they can help him rather than assuming they know what to do or grab him. At 71, Peterson said he is past retirement age, but the NDSU campus is what Peterson calls home. "I like the college environment," he said. "I like my contact with faculty, staff and students. ... this has become my life that I enjoy doing."

Source: Jack Dura, www.ndsuspectrum.com, 12 November 2015.

RESEARCH UPDATE

RetroSense Therapeutics' Lead Gene Therapy Candidate Gets FDA Clearance to Proceed to First-in-Human Clinical Trials

RetroSense Therapeutics LLC, a privately-held biopharmaceutical company, has announced the Company's Investigational New Drug (IND) application for RST-001 received clearance from the United States Food and Drug Administration (FDA). RetroSense is developing RST-001 for the treatment of retinitis pigmentosa (RP), a genetic condition that leads to the progressive degeneration of rod and cone photoreceptors (cells found in the retina that sense light), resulting in severe vision loss and blindness. With its IND now in effect, RetroSense expects to initiate a Phase I/II clinical trial by year-end in order to evaluate the safety and, potentially, efficacy of RST-001.

There is great promise for the clinical application of optogenetics and this first human clinical trial should provide key insights into the potential for this therapy to treat diseases affecting the eye or brain.

RetroSense Therapeutics is developing RST-001 as a first-in-class gene therapy application of optogenetics. Optogenetics refers broadly to means of conferring light sensitivity to cells that were not previously, or natively, light sensitive. By applying optogenetics to retinas in which rod and cone photoreceptors have degenerated, RetroSense is working to confer new light sensitivity to the retina, with the expectation of some degree of improved or restored vision for affected patients.

In 2014, the FDA granted Orphan Drug designation for RST-001 based on its development as a treatment of RP, a rare disease that affects an estimated 100,000 people in the United States. As a designated Orphan Drug, RST-001 is eligible for various development incentives under the Orphan Drug Act, including a potential waiver from FDA's application user fees, certain tax incentives and Orphan Drug exclusivity.

"The IND for RST-001 is an important milestone for the company. This brings us one step closer to realising our ambition of improving vision in those individuals with currently incurable blindness," said Sean Ainsworth, CEO of RetroSense Therapeutics. "There is great promise for the clinical application of optogenetics and this first human clinical trial should provide key insights into the potential for this therapy to treat diseases affecting the eye or brain."

Dr. Zhuo-Hua Pan, the inventor of RetroSense Therapeutics' optogenetic approach added, "My hope from early on was to see our work improve the lives of people with vision defects. It is great to see the approach moving imminently into human clinical studies."



Dr. Zhuo-Hua Pan

Source: Retrosense Therapeutics Inc, 24 August 2015.

Predictors of psychological distress in caregivers of older persons with wet age-related macular degeneration

OBJECTIVES

Several studies have investigated the biopsychosocial impacts of age-related macular degeneration (AMD) in regards to the older patient, but little is known about the impacts associated with caring for individuals with AMD. We aimed to determine the predictors of subjective caregiver distress and other negative outcomes associated with caring for someone with advanced AMD.

METHODS

A cross-sectional, self-complete survey involving 500 caregivers of persons with advanced AMD was undertaken. Respondents were identified from the Macular Disease Foundation of Australia client database. Logistic regression tested the independent effects of care recipient and caregiver characteristics on study outcomes, including: caregiver psychological well-being, participation in recreational/social activities and retirement plans.

RESULTS

Around one third of caregivers self-reported a high level of care recipient dependence. Over one in two caregivers reported a negative state of mind. Comorbid* chronic illnesses in the care recipient were associated with the caregiver reporting psychological distress, multivariable-adjusted odds ratio, OR, 1.45 (95% confidence intervals, CI, 1.14-1.86). If the care recipient was highly dependent on the caregiver, there was 99% greater likelihood of caregiver distress, OR 1.99 (95% CI 1.01-3.93). Comorbid chronic conditions in the care recipient was associated with 49% and 31% higher odds of the caregiver reporting disruption to other areas of their life and retirement plans related to the caregiving experience, respectively.

CONCLUSIONS

A high prevalence of caregiver distress related to caring for persons with advanced AMD was observed. Level of dependence on the caregiver and presence of comorbid chronic illnesses were independent predictors of the caregiver experiencing psychological distress.

Source: Aging Mental Health. 2015;19(3):239-46. Centre for Vision Research, Department of Ophthalmology and Westmead Millennium Institute, University of Sydney, Australia.

Definition- What is a comorbid* illness?

The presence of one or more additional disorders (or diseases) co-occurring *with* a primary disease or disorder. The additional disorder may also be a behavioural or mental disorder.

Source: en.wikipedia.org/wiki/Comorbidity

The role of electrical stimulation therapy in ophthalmic diseases

INTRODUCTION

Electrical stimulation therapy (EST**) involves the use of a low-intensity electrical current in the treatment of neuromuscular conditions. During the recent two decades, EST has emerged as a potential neuroprotective strategy in certain ophthalmic diseases, aided by a lack of effective management for these conditions.

PURPOSE

The aim of this review is to summarise and discuss current available evidence for the use of EST in ophthalmic diseases in the laboratory setting and in human trials.

METHODS

The compilation and review of published English-language reports on the use of EST in human ophthalmic disease and animal models of ophthalmic disease.

RESULTS

From published reports, research work on the use of EST in ophthalmic diseases began in the last 20 years. Different methods of electrical stimulation have been devised, with varying levels of invasiveness. Results from human trials have favored earlier and repeated treatment after insults to the optic nerve, while EST has shown transient effectiveness in degenerative diseases of photoreceptors. Patients also reported no serious adverse effects from EST in the clinical trials. Results from animal studies have further confirmed survival benefits of EST in retinal cell survival, with the underlying mechanism likely multifactorial, but involving Müller cell modulation.

CONCLUSIONS

Results from human and animal studies have demonstrated the relevance and potential effectiveness of EST in ophthalmic disease. However, optimal disease and species-specific stimulation settings need to be defined.

Source: Graefe's Archive for Clinical and Experimental Ophthalmology, 2015 Feb;253(2):171-6. Fu L, Lo AC, Lai JS, Shih KC, Department of Ophthalmology, Li Ka Shing Faculty of Medicine, The University of Hong Kong.

Definition - What is EST?**

The elicitation of muscle contraction using electric impulses. The impulses are generated by a device and delivered through electrodes on the skin in direct proximity to the muscles to be stimulated. The impulses mimic the action potential coming from the central nervous system, causing the muscles to contract. The electrodes are generally pads that adhere to the skin.

Source: en.wikipedia.org/wiki/Electrical_muscle_stimulation

Converting rods into cones in a model of retinitis pigmentosa (RP) rescues retinal degeneration

Inherited retinal disorders (IRDs) are estimated to affect millions of individuals on a global scale, in many instances leading to significantly reduced vision or blindness. The term “IRD” acts as an umbrella label for many different types of ocular disease and, on a genetic level, it is estimated that almost 200 distinct genes are the causative agent behind one or more inherited retinal pathologies.

Retinitis pigmentosa (RP), another large collection of ocular disorders, accounts for approximately 50% of known IRD cases. RP is probably one of the most heterogeneous diseases recorded to date, arising from mutations in more than 50 genes with over 3,000 mutations reported by mid-2013. In addition, many syndromic forms of RP also exhibit genetic heterogeneity which, when combined with incomplete penetrance and clinical heterogeneity, result in a significant medical challenge in terms of devising optimised clinical care strategies.

While RP can be initiated (literally) in thousands of different ways, the course of disease generally progresses through an increasing level of rod photoreceptor cell loss followed by cone photoreceptor degeneration. As such, most cases of RP have a common degenerative pathway of cone cell death following closely on loss of the rod cell population.

This common end-stage for the disease has given rise to a therapeutic strategy in which rod cells are “reprogrammed” to direct the cells down a cone cell fate. Directing cells away from rod differentiation and toward cone cell differentiation may, in theory, avoid the molecular pathology arising from mutations in rod-specific genes. To test such a hypothesis researchers at the Washington University School of Medicine carried out just such an experiment on animal models of RP.

Led by Drs. Cynthia Montana and Joseph Corbo, the US-based research reported the rescue of a retinal degeneration by the reprogramming of rods into cones. The study used a well-characterised retinal transcription factor to re-direct rods to a cone cell fate. The principle itself of course is not new. Conversion of one differentiated cell type into another has been carried out in other contexts, including the conversion of pancreatic exocrine cells into β -cells or, auditory endothelial cells into hair cells and fibroblasts into neurons.

Of course rod reprogramming is quite different in that the conversion itself would result in a loss of rod function followed by consequent night blindness. However, most individuals might agree that night blindness is an acceptable risk in the context of maintaining a healthy cone cell population and functional photopic vision. The result of the cellular reprogramming in this case reduced rod photoreceptor cell death in a rhodopsin knock-out model of retinitis pigmentosa.

As highlighted in the human pathology, the loss of the rod cell population has a deleterious impact on the cones which subsequently degenerate leaving patients with both reduced or absent photopic and scotopic vision. The results of the research suggest that maintaining a rod photoreceptor cell architecture may be sufficient to slow or halt cone cell degeneration.

To achieve their results the research team exploited the biology of the neural retina-specific leucine zipper (Nrl) transcription factor, known from many previous studies to determine photoreceptor cell fate in the retina. Under normal conditions, photoreceptor precursors expressing Nrl become rods whereas those without Nrl progress to a cone photoreceptor lineage. To knock out Nrl in a model of retinitis pigmentosa the research team generated a conditional Nrl knock out controlled through a tamoxifen inducible promoter.

A daily injection of 4-hydroxyl-tamoxifen (4-OHT), between postnatal day 42 and 44, caused inactivation of the Nrl transcription factor resulting in the reprogramming of rods to a cone cell fate. Assays of the reprogrammed pseudo-cones demonstrated a significant decrease in the scotopic ERG response suggesting a loss of rod function, while genetic analysis indicated a loss of expression of rod-specific genes, including rhodopsin, with a parallel activation of cone specific genes.

While the reprogramming of rods into cones was only partial and dependent on the timing of Nrl knock-out, the strategy nevertheless rescued the cone cell population within a model of RP. Keeping the rod cells alive, even dysfunctional rods harbouring mutations that cause RP, appeared to be sufficient to maintain the retinal architecture and thereby support cone cell survival.

In concluding their research the authors commented that, “apart from providing insights into the plasticity and maintenance of rod photoreceptor identity, the study demonstrated that partial rod-to-cone reprogramming can forestall retinal degeneration in the Rho^{-/-} model of retinitis pigmentosa. Although these cells are not true cones, they exhibit sufficient down-regulation of rod-specific genes to resist the deleterious effects of a rod-specific mutation”.

In addition, the research team suggests that the re-programming approach may also be employed to generate a novel cone cell population that could serve to rescue other retinal degenerative conditions, including age-related macular degeneration. While the results indicate the potential for this strategy in the rhodopsin knock-out model, other models of RP, including dominant forms, will need to be tested.

Finally, if such a therapeutic approach is ever to find application in a human population then a virally delivered approach to Nrl knockdown will be required. Thankfully, the success of AAV gene delivery to the retina in recent years has been a considerable success providing the necessary platform for an entrepreneurial drive to take the next steps.

Source: www.euretinabrief.org, Euretinabrief No 100, 2 July 2015.

HOLIDAY OPPORTUNITIES

In our September edition of The Achiever, our members Helena and Bill Irvin shared their experience of a tour to Queenstown, New Zealand with a group of vision impaired persons. Recently we have received news of two further travel opportunities which you may be interested in. Please contact the organisers directly for further information.

1. Orientation & Mobility Tour of Hong Kong 23th of June 2016



Independent Options
for Mobility

Training and Education for Independent Travel

Experience travelling outside Australia with experienced O&Ms as your tour leaders. Gain the confidence and satisfaction of independent travel visiting highlights throughout Hong Kong. Challenge your senses with highlights that include Hong Kong Disneyland, walking tour of Kowloon including markets and gardens, train travel to Shenzhen and street food tour.

Includes

- Experienced Orientation & Mobility specialist on tour
- Return airfare from Melbourne
- Airport transfers
- 7 nights accommodation based on twin share
- 7 x buffet breakfasts
- 3 x lunches
- 4 x dinners
- Tours as per itinerary
- Basic travel insurance



Total Cost \$4,150.00 per person

Conditions and exclusions

Price is based on twin share accommodation and economy airfares, full itinerary available upon request, above price does not include – personal expenses, tips for guides, escorts and drivers, pre-existing medical cover on travel insurance. All tour pricing is subject to change; above is shown as a guide only. Final pricing will be confirmed once booking has been made.

To request further information please contact Dean Johnson from Independent Options for Mobility on 0426 215 547 or email – dean@options4mobility.com.au

2. George Booth 2016 - Escorted Vision Impaired Tour of Singapore 6 Nights / 7 Days - Departing Australia Sunday 17th July 2016

For more than 10 years George Booth has designed and escorted tours for vision impaired persons to many cities in South East Asia, China and New Zealand delivering many exciting experiences appealing to the senses, with interesting content inclusions to ensure maximum enjoyment on tour. In 2016 an escorted tour of Singapore has been designed with flights departing from around Australia, as part of the opportunity to meet other like-minded persons, whilst holidaying in the multi-cultural garden city of South East Asia.

The activities include morning walks, open top bus tour, the National Orchid Gardens, the Bird Park and even lunch with the parrots. Leisure time mixed with the opportunity to shop, take optional tours and eating out together from our central base of Peninsula/Excelsior Hotel.

Cost Inclusions:

- Economy class flights Australia to Singapore and return flying Singapore Airlines
- Current airport taxes and charges
- 6 nights at Peninsula/Excelsior Hotel (twin share)
- Full buffet breakfast daily
- Two morning walks (China Town & Singapore River)
- Open Top Bus tour with Satay Dinner at Lau Pa Sat
- Afternoon tour to Little India/Malay Heritage Centre and National Orchid Gardens
- Bird Park Tour with lunch included & Singapore by Night tour with dinner included
- Tour Escort on tour (subject to minimum 20 persons)



Note:

- Optional tours will be offered for those wanting to experience more of Singapore.
- It is compulsory to have a sighted companion for the duration of the tour.
- Travel Insurance is compulsory.
- A valid Australian passport with at least 6 months validity is required.
- A deposit of \$250.00 per person is required within 7 days of confirmation with the balance due 8 weeks prior to travel.
- Prices are based on minimum tour numbers met.

Tour Costs: Per Person - Twin Share

\$2640.00 per person Ex Perth and \$2840.00 Ex Adelaide/Melbourne/Sydney/Brisbane

For more information or to make a reservation contact:

Ms Faye Pafumi on (08) 9382 5082 or Email: faye@traveltree.com.au

George Booth and Faye Pafumi - Travel Tree

First Floor, 3 Rosslyn Street, West Leederville WA 6007

t: (08) 9382 5011 or w: traveltree.com.au

Question Time

With Naomi Boyd

Naomi Boyd has kindly volunteered to finish off the year of this popular column featuring our members.



1. What's your earliest memory?

My earliest memory was on my fifth birthday. I was on holiday in Apollo Bay at a hotel apartment with two storeys and stairs. I remember my birthday cake had 5 twirling ballerinas on it and it was pink. I loved it!

2. What's your idea of a good time?

I love watching movies and some TV, when you can really involve yourself in the show. I also love going on holidays with my son.

3. Who inspires you?

My Mum and Dad inspire me for different reasons. Mum, because she gives her time and love so generously and freely to family, friends and everyone. Dad, because even though he has a vision impairment, he hasn't let that stop him in his life and he has achieved so many fantastic things.

4. What makes you angry?

People being discriminated against because of their disability, race, religion etc. I think it's so important to accept everyone regardless of their background.

5. If you could change one thing about the world, what would it be?

I would hope that more people would know God and become a part of a church community. I would also like to change the corrupt governments that are in many parts of the world to help improve the lives of people living there.

6. What do you like about Retina Australia (Vic)?

I like the fact that you are kept up to date with what is happening research-wise into retinal diseases. There is also lots of support available which is fantastic.

7. What's the most important thing you've learnt about life?

The most important thing I've learnt is to take each day at a time and to not worry what is going to happen the next day. This is also one of the hardest things to do too!

8. What's your ideal holiday destination?

My ideal holiday destination would be England. My Mum is from England and I have always wanted to have a holiday there, but I've never been able to go. It'd be great to see family, the history, and the beautiful countryside.

9. What's the hardest thing you've ever done?

At university I did a few months exchange to Indonesia as part of my Business course. I went to an Indonesian university, with lectures in Indonesian, and I stayed with an Indonesian host family. What made it extra challenging was that I already had significant vision impairment, so sometimes this made getting around difficult.

10. What's the best thing you've ever done?

The best thing I've done is when I had my son Daniel 7 years ago. It has been 7 years of love, learning and enjoying good times and sometimes challenging times together. I wouldn't change it for anything!

Would you like to feature in Question Time in 2016? Contact the office to find out how!

FUNNY CHRISTMAS QUOTES

"The Government has decided that they cannot have a nativity scene in the city. This wasn't for any religious reasons. They couldn't find three wise men."

"Santa Claus has the right idea. Visit people once a year."

"Christmas is cancelled. I told Santa you were good this year and he died laughing!"

"The awkward moment is when Santa Claus has the same wrapping paper as your parents."

"A song told me to Deck the Halls, so I did. Mr and Mrs Hall are not very happy."

"I once bought my kids a set of batteries for Christmas with a note on it saying "Toys not included".

Last Word

Christmas is not a time nor a season, but a state of mind.
To cherish peace and goodwill, to be plenteous in mercy,
is to have the real spirit of Christmas.

CALVIN COOLIDGE, 1872 – 1933
30th president of the United States

I will honour Christmas in my heart,
and try to keep it all the year.

CHARLES DICKENS, 1812 - 1870

CHANGE OF ADDRESS OR OTHER DETAILS

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**

NAME:

NEW POSTAL ADDRESS:

.....

..... **POSTCODE:**

TELEPHONE/S:

NEW EMAIL:

DISCLAIMER:

Views expressed in this publication are not necessarily those of Retina Australia (Vic) Inc. Retina Australia (Vic) Inc accepts no responsibility and disclaims all liability for such views as well as for any information contained in articles and summaries of research reports, including but not restricted to, the use of pharmaceuticals or other products, items of equipment or practices. Retina Australia (Vic) Inc strongly suggests that persons seek advice from their medical practitioners before adopting any changed procedures, practices or products.



If undeliverable, please return to:

Retina Australia (Vic) Inc.

4th Floor, Ross House
247 – 251 Flinders Lane,
Melbourne, VIC 3000
www.retinavic.org.au

**SURFACE
MAIL**

**POSTAGE
PAID**

**“The Achiever”
Print Post Approved
PP33 1088/00107**