



THE **ACHIEVER**

Retina Australia Victoria
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WINTER EDITION

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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

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WONDERFUL WINTER

- Huge developments in worldwide research
- Clinical trials on the horizon
- Autumn raffle success
- Forum held for country expansion of Retina Australia Vic
- Leighton & Rosemary Boyd appointed to the Board of Directors of Retina Australia Ltd

PP: 33 1088/00015

From the President

Many donations were received for the Autumn raffle, which raised over \$2,200.00 We thank the generosity of all the donors.

Speaking of donations, the VLBA donation funds continue to serve us well in technological acquisition, investments, and indeed expanding our services.

Recently, a selected group of members representing Warrnambool, Geelong, Bendigo and Gippsland visited our Ross House office for a Saturday morning meeting. This meeting was held as the first step in a process hoping to broaden the reach and scope of Retina Vic across Victoria.

A number of exciting ideas came out of the meeting, which will all be announced in the near future.

This edition of the Achiever brings the news of breakthroughs in research overseas, and for those attending the upcoming Retina International Congress a bright future.

Retina Australia (our national body) has re-grouped over the past few months with Graeme Banks OAM settling into his new role as President. Graeme visited Melbourne recently to attend one of our Board meetings to update our Board on the future of the national body.

To this the national body now welcomes back Leighton & Rosemary Boyd as the Victorian representatives.

The vision is ours,

Charles Rogers
President

Vice-President – Jane Evans
Secretary – Rosemary Boyd
Treasurer – Graham Owen
Council members: Fiona McNabb, Leighton Boyd & Rick Clarke
Vision 2020 Australia Representative – David Foran
Administration Officer – Mary Maga



Left: Charles Rogers gives the acceptance speech at the 2007 VLBA AGM. Right: Graham Owen holding the cheque with Dave Byars & Charles Rogers to his left, Leighton Boyd to his right.



Autumn Raffle Prize winners

Thank you to everyone who participated by purchasing tickets.

The autumn raffle was highly successful and raised in excess of \$2200 for research.

	PRIZE	TICKET	WINNER	SUBURB
1	Warrnambool accommodation & Nestle basket	5191	Gordon Fraser	Ivanhoe
2	Carmel's Hamper	2836	Deb Thomas	Kew
3	Golf for two & easter egg basket	805	Yvonne Sher	Glen Iris
4	Wild about you Hamper	4308	Samantha Hore	Werribee
5	Chocolate box Hamper	4597	John Keane	Mt Eliza
6	Surprise Easter package	5145	Rosemary Boyd	Greensborough
7	Golf Balls & Lizzies chocolates	1616	Spiros Damoulianos	Clayton South
8	Clock Radio	3405	Harry & Diana Gibson	Rochester

A big thankyou to the following individuals and businesses who donated all of the prizes.

Mantra Deep Blue Resort, Nestle, Carmel Georgalas, Safety Beach Country Club, Coolaroo Chocolate shop, Wild about You, The Chocolate Box, Lizzies Chocolates, Haighs chocolates, Chocoholic Tours, and Maree Rogers

Have you heard...

China has approximately 12 million blind or vision impaired people. To date little has been done to support them, but now some financial aid is being offered. In Beijing footpaths are being levelled and made smooth. Guide dogs are almost unknown in China. The first school for guide dogs opened in 2006, and to date there are only 4 working dogs in the whole of China. Many cities have ordinances against the keeping of large dogs, those over 35cm high. A newly trained guide dog handler living in Beijing, despite wanting to be independent, has had to register her dog as a pet and use it only in her home and business. Officials have offered to bend the rules for the Olympics, little consolation to China's blind community.

Courtesy of the Newsletter of Retina New Zealand Inc – summer Newsletter February 2008 No 36

Quiet Revolution – A word from the Vice President

Over the past 12 months there has been a quiet revolution happening behind the scenes at the Retina office in Ross House. New equipment and new systems have greatly increased efficiency as well as providing volunteers with a more workable environment.

A small part of the funds donated by the Victorian Lady Bowling Association has been earmarked to upgrade equipment and replace worn out furniture. These funds have been used to buy a new CCTV for the office; to replace the old computer screens with a new large screen format; and to purchase a new combined printer, photocopier, scanner and fax machine. Ergonomic chairs have been bought to replace the old, uncomfortable office chairs.

Other improvements include: networking the three computers so that the same version of a document is available to everyone at the same time; upgrading the software on all machines with Microsoft XP Professional operating system; and purchasing an external hard drive to which all documents are saved overnight, thus providing a secure back up.

After some research, a membership data base software application has been purchased that will greatly enhance Retina's ability to store relevant information provided by members and donors. Judi Potts is currently working on inputting details to this new database.

Since moving to the new office location, a number of different set-ups have been tried to get the most effective layout of office furniture and equipment. Leighton and Rosemary Boyd, two of our most active and energetic Board members, have recently gone through all the documents on file to cull out duplicate and unnecessary paper. Over time, these documents will be scanned and stored electronically, ensuring a safe record of Retina's affairs and history.

Functions in our MYOB accounting system have been activated so that an inventory of Christmas Cards, Owl Badges, Key Rings and Entertainment Books can be maintained and our assets properly recorded. Considerable work by Graham Owen and others has improved the quality of financial information provided to the Board.

Last but not least, the Board has recently appointed Mary Maga as Retina's Administration Officer. Mary's willingness to listen and learn, as well as her administration experience, have already had a positive influence on the office.

Retina is always looking for Volunteers to assist with providing information and support to our members. If you would like to experience our new office set up first hand by volunteering to help please contact Mary on 9650 5088 or email support@retinavic.org.au

Jane S Evans
Vice-President
Retina Australia Victoria



FIGHTING BLINDNESS

PRESS RELEASE

RETINA AUSTRALIA LTD

ACN 059 846 829

Patron: Ian Healy

28 Station Street

THORNLEIGH NSW 2120

10 May, 2008.

PROGRESS WITH TREATMENT OF GENETIC BLINDNESS

In a world's first, teams of ophthalmic surgeons in the UK and the USA have achieved positive results from the introduction of a gene therapy into the retina of the eyes of humans affected with a retinal dystrophy (genetic blindness).

The genetic blindness involved in the trials is Leber's Congenital Amaurosis (LCA), a particularly 'virulent' type which affects persons with this genetic defect either from birth or from a very early age.

Mr Graeme Banks, President of Retina Australia says the progress that has now been announced is exciting, especially given the demonstrable difference that has been made to the vision of the participants in Phase 1 of the trials, and taking into account that only low doses of the gene therapy were used. He said the main initial aim was to assess the efficacy/safety of such therapies.

"Whilst these initial gene therapy human trials commenced in the UK and the USA early in 2007, human gene therapy trials are also being progressed in Australia at the Lions Eye Institute, Perth, with the support of Retina Australia", Mr Banks said. "The very promising results from these first trials will provide the impetus for further work not only with the LCA gene but also with other genes responsible for genetic blindness, as the principles will be the same. "

Mr Banks said that research to find the genes responsible for retinal dystrophies such as LCA, Retinitis Pigmentosa, Macular Degeneration, and Stargardt's Disease, commenced in the early 1980s with the number of variations expected to total around 350 when they are all isolated. However, as specific genes have been found, work has commenced on developing a gene therapy for each one. He explained that the gene therapy has to be specific for each retinal dystrophy!

"One of the major tasks now faced by Retina Australia is the development of a genetic register of persons with retinal dystrophies whereby affected persons may, voluntarily, provide a blood sample from which their genetic material will be extracted. The aim is to determine their specific errant gene so that as gene therapies become available in the future there will be knowledge as to who will benefit from each specific therapy."

The ultimate aim is to provide the opportunity to all persons in Australia with genetic blindness, and their families, to benefit from gene therapies as and when they come on line.

Graeme Banks OAM
President

...Continued over page

Full details of the work done by the surgeons in the UK and USA are outlined in the reports accompanying the Press Release. If you are interested in obtaining copies of the very detailed information , please contact the office.

Background Notes

Excluding the genes responsible for Macular Degeneration, one in every 80 persons world wide is a carrier of a gene causing genetic blindness.

This translates to one in every three thousand persons being directly affected with genetic blindness in some form. Retinitis pigmentosa and macular degeneration are the major types of genetic blindness.

Retina Australia is undertaking a major public awareness exercise aimed at informing persons with retinal dystrophies of the organisation and the services it can offer through its State bodies.

Retinal dystrophies are the major cause of youth blindness and in the working age population are second to diabetes as the cause of vision impairment. Macular degeneration is responsible for most of the vision impairment in persons over the age of 55 – one in three with persons over 75 years.

Graeme Banks OAM

Lutein, Zeaxanthin and AMD Study 2008

The Centre for Vision Research at the University of Sydney, Australia, studied the dietary and supplement intakes of antioxidants and the long-term risk of incident age-related macular degeneration (AMD). Over 10 years, 2454 participants were examined and re-examined. Those participants that had higher amounts of lutein and zeaxanthin intake had a reduced risk of incident neovascular AMD and those with above median intake had a reduced risk of soft or reticular drusen.

The study concluded that the higher dietary lutein and zeaxanthin intake reduced the risk of long-term incident AMD. It also confirmed finding protective influences from zinc and beta-carotene to help lower the risk of AMD, as did the 10 year study by the US National Institute of Health's Age-Related Eye Disease Study (AREDS).

Ref: J.S.L. Tan, J.J. Wang, V. Flood, E. Rochtchina, W. Smith, P. Mitchell. "Dietary Antioxidants and the Long-term Incidence of Age-Related Macular Degeneration: The Blue Mountains Eye Study." Ophthalmology (Elsevier). February 2008, Volume 115, Issue 2, Pages 334-341.

Sensory Gardens

Many people who are blind or vision impaired would like to create a garden that appeals to their senses. Sensory gardens are designed to be enjoyed through touch, taste, sight, smell and hearing. If you are a beginner, the key to success is to start in a very simple way such as a pot of mint.

Perfumed Flowers

Compare the perfumes of different flowers such as roses, camellias, gardenias, jasmine, buddleia, heliotrope, fruit trees, osmanthus, portwine magnolia, stephanotis, viburnum and honeysuckle.

Aromatic foliage

Herbs with aromatic foliage provide different smells and textures. These include lavender, basil, thyme, menthol mint, rosemary, lemon verbena, applemint, chamomile, pineapple sage, chives and wormwood.

Sounds in the Garden

Several flowers, plants and trees such as casuarinas and robinias make unique sounds in the wind. A wind chime can provide a pleasant sound when a breeze blows through the garden. Water features can have soothing sounds. Many nectar-rich plants and flowers attract an abundance of birdlife. Installing a bird bath provides a place for birds to drink and splash!

Tastes From the Garden

Tease your tastebuds by planting fruit trees, vegetables or herbs. Try mandarin trees, passionfruit vines, lemonade trees, peas, tomatoes and carrots or parsley, mint and basil.

Finding Your Way Round the Garden

Reference points can be used to help you locate different areas within your garden. For example, place a statue in proximity to the herbs. Remember to keep paths free from obstacles and hazards.

Visit the Vision Australia sensory garden at Enfield NSW if you are interested in seeing such a garden for yourself.

Information obtained from the Vision Australia website

Question Time

This is a new column in which we will randomly ask volunteers to answer ten questions about themselves. Besides providing some lighter reading, this column is intended to focus on members by giving us the opportunity to get to know each other and contribute towards our sense of community. Let's share and find out about others who have had common experiences through either being directly affected by retinal dystrophies or associated with those who are, such as partners, friends and volunteers. Everyone has a story to tell through their personal life journeys which can entertain, inform, and inspire! **Rick Clarke**



1. What's your earliest memory?

Getting lost on the beach at Ocean Grove on a family holiday when I was about 5.

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

Fine food and wine, and great company to share it with!

3. What's your ideal holiday destination?

Ay Island - an isolated small island in the Molluccas, the spice islands of Indonesia. Beautiful beach and sunsets, unspoilt scenery, great people, fresh tuna, no shopping centres or vehicles, and cheap!

4. Who inspires you?

People who have had to face huge hurdles or setbacks in their lives, who go on not only to survive, but thrive with a sense of purpose and determination to achieve great things and make a positive difference to other people's lives.

5. What makes you angry?

Corruption, greed, repressive regimes, and when economic imperatives invariably take precedence over upholding basic human rights and environmental conservation.

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

Come to terms with a diagnosis of RP and deal with the on-going associated emotional issues and adjustments in life.

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

Joined the Australian Volunteers Abroad program and worked as an English teacher in a senior secondary school for two years in a village on the Indonesian island of Flores.

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

The opportunity to support positive initiatives aimed at finding treatments for retinal illnesses, the opportunity to meet others facing similar issues, and the opportunity to work with dedicated volunteers.

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

Eliminate poverty so that everyone has enough to eat and access to basic medical care.

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

The universal law of attraction – you reap what you sow.

Don't hold back! Volunteer today to feature in an upcoming Question Time, or to contribute an interesting personal life story you would like to share!

Research at Lions Eye Institute,

University of Western Australia

In Australia, Prof Rakoczy and her team at the Lions Eye institute, Perth, successfully applied gene therapy for LCA using a dog model of the disease. Following gene therapy, the vision impaired dogs showed remarkable improvement in their sight. After this success, the team focused its attention on Age Related Macular Degeneration (AMD).

In general, ocular gene therapy is used to produce a particular protein that is either not present or present, but is non functional in the eye due to a genetic mutation. Unfortunately, the genetic mutation is not always known thus limiting the usefulness of gene therapy. Hence, development of strategies that do not require the knowledge of the mutation is very important.

AMD, which is the major cause of blindness in the developed world, is a complex disease. While genetics may play an important role, the genetic mutations causing AMD remain unknown in most cases. To be able to tap into the long-term benefits of gene therapy for the treatment of AMD, Prof Rakoczy and her team has developed the concept of Secretion Gene Therapy. Here, the same recombinant virus delivery system used for the human LCA trials is utilised to produce a natural soluble protein. This natural soluble protein is able to neutralise the affect of factors responsible for promoting the growth of damaging new and leaky blood vessels seen in the wet form of AMD. Preclinical trials showed remarkable inhibition of these damaging blood vessel growth and leakiness and maintenance of vision. Prof Rakoczy is in the final stages of gaining approval from the TGA for human trials in Australia and she hopes to start clinical trials later this year.

(This research was conducted with the support of Retina Australia).

Entertainment Books

One of our many continuing fundraisers is now offering the 2008-2009 book. Featuring thousands of coupons to gain discounts at eateries, entertainment venues and travel.

Ideal last minute birthday or anniversary present for only \$65 (Melbourne edition) or \$50 (Geelong/Ballarat edition). Contact the office for further enquires and purchases.

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Retina Australia (Vic) Inc.

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

“The Achiever”

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